Respectful Death:
A Model for End-of-Life Care

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The Respectful Death Model (RDM) is a research-based, holistic, and practical model developed to improve end-of-life care. A respectful death is one which supports dying patients, their families, and professionals in the completion of life cycles and can be used by all members of the healthcare team. The model is a process method commencing with the establishment of a therapeutic relationship with the dying patient and his or her family and, as a result, their stories are heard and incorporated into the care plan. This article demonstrates that hospice and palliative care nurses have been practicing this model since the origination of care of the dying. Other topics addressed are the current culture toward death in the United States, the roles of nurses in the RDM, and the barriers and benefits of the RDM. Recommendations for future research in end-of-life care also are addressed.

At a Glance
- The Respectful Death Model (RDM) is a practical, research-based holistic tool meant to foster the education of varied disciplines in end-of-life care.
- The RDM details the establishment of therapeutic relationships with patients and their families and, as a result, their stories are heard and incorporated into the care plan.
- Nurses establish therapeutic relationships with their patients and families, ensuring frank dialogues about death and resultant respectful deaths.

Examples include expressions such as “he or she passed on” or “he or she is at rest,” rather than saying “he or she died.” Death is still a taboo topic. Becker (1973) stated that the fear of death is universal, and Kastenbaum (1978) noted that the study of death may improve the quality of all civilization by eliminating painful deaths.

In any discussion about death, suffering often is used simultaneously. The Respectful Death Model (RDM) requires healthcare professionals to listen to the dying to help relieve their suffering (Farber & Farber, 2006). Cassell (2004) defined suffering as the stress that occurs as a result of losses, including loss of family, friends, possessions, roles, relationships, a future, and physical losses related to bodily functions. Suffering...
occurs within relationships; the nature of these relationships, according to Cassell, influences the degree of suffering that is experienced. However, this thought is contrary to some current theories about death and suffering because of the tendency to use medication to relieve suffering (Byock, 1996).

### Pioneers in Changing Attitudes

Although some 30–40 years have passed since champions such as Saunders, Feifel, Quint Benoliel, Folta, Glaser and Strauss, and Kubler-Ross pioneered work with the dying, U.S. culture has not significantly changed its attitude toward death. Saunders, a nurse, social worker, and doctor, began her work in the East End of London in the late 1950s and founded St. Christopher, the first hospice (Clark, 1999). She defined and described a theory of total pain: that the dying suffered not only physical pain but “emotional, spiritual, psychological, and social pain” (Clark, p. 729). Feifel edited the first comprehensive book in 1959, *The Meaning of Death*, in which topics such as modern art and death, the treatment of the dying, and attitudes toward death by healthy and mentally ill populations were addressed.

Quint Benoliel, a nurse researcher, published a book and several articles on caring for the dying and was one of the first to do research on the dying in teaching hospitals (Quint Benoliel, 1977). She described the care/cure dilemma and that the existential or human aspect was missing from this care.

Folta, also a nurse researcher, described death as “multi-complex.” She studied the attitudes and perception of death of various nurses at several sites (Folta, 1965). Her research revealed that, despite the fact that death was perceived as peaceful, nurses described their attitudes as fearful and anxious. Folta concluded that this fear might be a universal human reaction or that it may be because her particular groups of nurses feared death and, therefore, chose nursing as a career to help prevent it.

Glaser and Strauss (1965) also studied the dying in hospitals and developed a theory about the awareness context surrounding death, referring to the knowledge that the dying patient, caregivers, and family hold regarding the fate of the patient (Glaser & Strauss).

Kubler-Ross, a psychiatrist, talked with dying patients in hospitals in the 1960s and was one of the first to address the public about dying (Kubler-Ross, 1969). She developed a stage theory describing various emotions and considerations that people experienced when confronted with death (Clark, 1999).

### Realities of Death

We are mortal and aware that we will die. We mourn and bury our dead with some cultures believing that death is a personal, unique, and private journey of an individual whereas others see it as a public event (Byock, 2002; Vig et al., 2002). The responsibility of caring for the dying rests with individuals and communities because of shared mortality and the effects each death has on individuals and communities (Braun, Zir, Crocker, & Seely, 2005; Byock, 2003).

Another thought on death is that it is a natural part of life, a stage in which the dying attempt to find meaning in their lives and of life in general (Byock, 2002). The old die to make way for the new; death makes way for the birth of children (McCue, 1995). Many authors today, just as the early pioneers did, advocate for a holistic approach to end-of-life (EOL) care, bringing attention to the physical, spiritual, emotional, and social needs of the patient (Dobratz, 2005; Mariano, 2001).

### The Dying Process

Western medical and bioethical decisions reflect the importance of individual autonomy and personal choice in healthcare decisions (Volkmer, Kahn, & Pinto, 2004). The Patient Self-Determination Act of 1991 gave hospitalized patients the right to make treatment decisions, which led to the formation of advance directives and gave patients the right to refuse life-sustaining treatments (Bookbinder & Kiss, 2001).

A study of more than 4,400 seriously ill and older adult patients by Lynn et al. (1997) revealed that most died in acute care hospitals and often suffered from pain and other symptoms. The study also revealed that family members interviewed after the death of a loved one confirmed that life-sustaining treatments were performed despite their wishes for comfort only. The U.S. Department of Health and Human Services (2006) revealed that, in 2004, 2,401,400 U.S. residents died. Of those, 903,953 (37%) died in inpatient hospitals or medical centers, the highest percentage for any one location. Other locations included at home, in nursing care facilities, and in emergency rooms.

Walter (1996) suggested that the original discourse on death emanated from the church, which supported the dying and their families. However, the 20th century saw a shift from the church to modern medicine and the hospital setting (Walter). Sullivan (2002) described hospitals as institutions that value saving lives and favor acute care rather than care of the dying. The discourse changed in the late 20th century to “living with dying” because of the extended life expectancy of patients living with life-threatening diseases (Walter).

The culture of dying in the United States, however, has been rocked by media coverage of the Terri Schiavo case; the death of Pope John Paul II (Lazar, 2005); the deaths from the September 11, 2001, terrorist attacks; and the deaths of soldiers and civilians in Iraq and Afghanistan in the war on terror (Gallo-Silver & Damaskos, 2004). How those events will affect cultural views on dying is unknown.

### The Respectful Death Model

The RDM is a research-based and holistic model developed out of a qualitative study of patients with cancer funded by a grant from the Project on Death in America (Open Society Institute, 2008). The original purpose of the research was to establish an EOL curriculum for family practice residents in the School of Medicine at the University of Washington (Farber, Egnew, & Farber, 2004). Working collaboratively with patients with cancer, their families, and their healthcare providers, researchers were able to conduct focus group studies about EOL concerns. RDM evolved from the focus groups and a workbook was created to assist patients and their families with EOL concerns (Farber et al.)

Respectful death and the RDM of EOL care can be used by all members of care teams. The process method and the roles
of nursing in the RDM will be described and the benefits and barriers will be discussed and support for the model provided (see Figure 1).

Respectful Death and the Model of Care

A respectful death is one which supports dying patients, their families, and healthcare professionals in the completion of the life cycle (Farber et al., 2004). This necessitates an intimate and personal relationship with patients and families; therefore, it is a model “that acknowledges the power of relationships and invites [professionals] to be mindful, curious, and open to surprises” (Farber & Farber, 2006, p. 223). An intimate and personal relationship is natural for many hospice, palliative care, and other nurses, but some members of the healthcare team may need mentoring by experienced nurses to practice these roles. Nurses have always formed therapeutic relationships with their patients and have been in the forefront in caring for the dying, as evidenced by the hospice movement in the United States. Examples of the writings of hospice and palliative care nurses and the work that they have accomplished are illustrated in Final Gifts (Callanan & Kelly, 1997) and All Kinds of Love: Experiencing Hospice (Jaffe & Ehrlich, 1997).

One result of the formation of these intimate and therapeutic relationships is that patients’ and families’ stories are heard, and, as a result, are incorporated into the care plan (Farber & Farber, 2006). Each individual has different tasks he or she would like to complete at EOL, including reconnecting with lost family, saying goodbyes, and forgiving others. One role of healthcare professionals in the RDM is to help the dying and their families complete these tasks (Farber & Farber).

Farber et al. (2004) clarified that the point of entrance for EOL care should occur when the professional determines that a patient could die within a year. The model describes how to begin communication about death and how to explore patients’ and families’ knowledge of death (Farber & Farber, 2006). Nurses in all settings must begin this communication about death with their dying patients and families.

Farber and Farber (2006) discussed the issue of cultural diversity and claimed that every relationship is cross-cultural. A patient’s experiences, beliefs, race, gender, and socioeconomic class help define who the patient is and his or her meaning of life (Farber & Farber). The responsibility of healthcare professionals is to discover and understand the individual cultural experience and use that information in the care of patients and their families.

Establishing a Therapeutic Relationship

The story of the patient and his or her family is obtained by establishing a therapeutic relationship and “mindful listening” (Farber & Farber, 2006, p. 223). Professionals must first examine their own values and beliefs surrounding death prior to working with the dying (Farber et al., 2004). Establishing relationships and mindful listening is accomplished through “commitment, connection, and consciousness” (Farber & Farber, p. 223). Commitment refers to the fact that professionals will not abandon the patient when they are dying and will remain by their side until the end (Farber & Farber). Establishing connections means that the patient and family can discuss all topics of importance, such as the existential questions of life, and receive responses from the healthcare professional caring for them (Farber & Farber). Consciousness refers to experiences and life meanings shared by the patient and his or her family (Farber & Farber).

Farber and Farber (2006) also informed healthcare professionals on how to begin dialogues about death. One of the first pieces of knowledge to ascertain from the patient is what understanding he or she has of the illness (Farber & Farber). Another important question is “who would you like involved in your healthcare decisions?” (Farber & Farber, p. 233). A patient’s beliefs about the future also should be determined (Farber & Farber) and an understanding of the dying process should be clarified if misunderstood (Farber & Farber). A patient’s fears and hopes also are critical pieces of information, as is determining the patient’s past experiences with crises (Farber & Farber).

Benefits of the Model

The formation of the therapeutic relationship, the exploration of the patient’s and family’s knowledge of death, and listening to their stories aids in the clarification of EOL issues and helps provide solutions that reduce conflict and suffering (Farber & Farber, 2006). Life stories often are remembered and retold, or are written down, to benefit future generations in their understanding of life and death (Farber & Farber). Another benefit of the model is the potential for growth and learning experiences for the patient, family, healthcare professionals, and commu-
nity (Farber & Farber) and the ability of the patient to achieve respectful death and complete his or her life cycle.

Caring for patients in EOL can be a privilege. Healthcare professionals experience the personal satisfaction of helping to heal during this time, are reminded of the beauty of life and nature, and may experience a deeper understanding of life and death. Healthcare professionals have the satisfaction of providing a service to the community, such as being a witness to suffering or educating others about EOL issues (Farber & Farber, 2006). Farber and Farber defined for healthcare professionals when patients should be informed that they are dying, which has been lacking in other models of care, and instructed healthcare professionals on how to communicate the important issues of EOL to patients and families. The RDM is, therefore, a practical model that can help educate professionals in the holistic care of the dying. Decisions regarding the myriad of choices that are required will be less of a burden to families and communities because of these dialogues.

The RDM dissolves the value judgments of healthcare professionals and returns the process to the patient and family. The lived experiences of the patient and their family are important in this model (Farber & Farber, 2006). The focus on patients and families and their preferences and meanings, along with needed healthcare system and policy changes, can pave the way for respectful deaths.

Support for the Concept of Respectful Death

Many authors have written about the importance of patient-provider communication and obtaining stories from patients and their families. Saunders used patient narratives as an important methodologic tool in her research (Clark, 1999). Suchman and Matthews (1988) described healing as a connection between the patient and provider in which the patient feels that his or her concerns are listened to and heard. Amato (1990) acknowledged that people have to tell their stories and that their stories provide truths and legacies for those who survive. Nuland (1994) stressed listening to the patient and stated that “I would listen more to the patient and ask [him or her] less to listen to me” (p. 253).

Chokyi and Shlim (2004) stated that the healthcare professional is the main focus of hope for ill and dying patients. Kubler-Ross (1969) also said that EOL care should be based on the experiences, needs, and responses of the patient. The words of a patient in Crossing Over: Narratives of Palliative Care (Barnard, Towers, Boston, & Lambrinidou, 2000) illustrate the importance and benefits of the therapeutic relationship and mindful listening.

Well, you know, you got to find out about the identity of a person to get to know them. Because if you don’t know a person, you got to find out about his identity, go where he lives, where he goes, where he was born, who’s in his family. He’s got to open up, and tell you these things. Because the more you know about this person, his family, then that’ll make you know more about you. (Barnard et al., 2000, p. 2993).

Frank’s (1995) The Wounded Storyteller: Body, Illness, and Ethics describes the telling of stories during illness and dying. According to Frank, the stories are told because of the changes that illness brings to the body. Frank believed that the stories served two functions: a personal one in which the stories help the individual make sense of the illness and the changes to his or her concept of self, and a social one, in which stories require a listener to hear them. Frank also described storytelling as the turning of suffering into testimony and that the listeners, in turn, become witnesses and bear responsibilities of communicating the knowledge to others.

Barriers to the Respectful Death Model

Linda Emmanuel, vice president of ethics at the American Medical Association and an author in EOL care, said, “We have an entire healthcare system not friendly to EOL care, a workforce not educated to EOL care, and an entire population just climbing out of the era when it was taboo to talk about it” (Grady, 2000, p. A1). That sentence succinctly describes the barriers to all EOL models of care.

The first barrier with the RDM that Farber and Farber (2006) identified was that the medical culture in the United States does not usually allow time for, or ignores, patient and family input. Physicians often are not compensated for “just” talking with patients and nurses often are focused on the physical tasks of intensive care and oncology units with little time left to listen to patients and families.

A second barrier is that healthcare professionals must let go of their views as experts and become “guides, collaborators and consultants” (Farber et al., 2004, p. 115), a difficult task because of the loss of control they feel and their adherence to a biomedical model of care (Farber & Farber, 2006). The model of care refers to the fact that death is viewed as “a lingering biological accident rather than a biological inevitability” (Callahan, 2005, p. 11).

Another barrier that Farber et al. (2004) addressed is the comfort level in practicing something new. The therapeutic relationship of the nurse and the dying patient has been well documented (Perrin, 2001; Quint Benoliel, 1977; Rando, 1984). Nurses are the ideal providers to elicit stories or narratives, as they spend the most time with patients and interact with their families and other caregivers (Krammer, Ring, Martinez, Jacobs, & Williams, 2001; Witt Sherman & LaPorte Matzo, 2001).

Conclusion and Discussion

This article has highlighted the current culture of death in the United States, which is still one of denial and fear. However, the culture and discourse may be changing because of media coverage of high-profile deaths, tragedies such as the September 11, 2001, terrorist attacks, and deaths of soldiers and civilians in the war on terror (Gallo-Silver & Damaskos, 2004; Lazar, 2005). However, many Americans still die in physical, emotional, social, psychological, and spiritual pain (Steinhauser et al., 2000; Vig et al., 2002).

The RDM is a holistic and research-based model describing the establishment of a therapeutic relationship with the dying patient and his or her family and listening to and incorporating their stories into the care plan (Farber & Farber, 2006). This exploration and resulting knowledge aid in the clarification of and offer solutions to issues that occur in the EOL setting.
thereby reducing conflict and suffering (Farber & Farber). Many hospice, palliative care, and other nurses have been practicing this model for many years, but others should incorporate it into their care by mentoring with experienced nurses and practicing the RDM.

The U.S. culture is trending toward a change in EOL care. Patients will benefit from dialogues about death with healthcare professionals, their families, and their neighbors. The RDM encourages dialogue to take place. The collective voice of professionals in the field of EOL care and health care in general has a responsibility to the community to foster dialogue for the good of the entire patient population (Byock, 2003). In addition, dialogue should take place prior to patients becoming too ill or unable to speak, so that their beliefs, values, and stories can be told and incorporated into care plans.

One area of research that should be considered is the dissemination of the RDM to all healthcare professionals working with patients. This may increase the initiation of dialogue with dying patients in a more compassionate and timely manner and, as a result, also may contribute to an increase in referrals to hospice or palliative care. A diffusion of innovations model (Oldenburg & Parcel, 2002) could accomplish this by first educating a core group and then having the group disseminate the knowledge to others.

Another area of research should be addressed by nurses and other researchers is the prevention of chronic illnesses and improvement in long-term care and quality of life for older adults (Callahan, 2005). The RDM of EOL care, along with needed healthcare system and policy changes, may help patients achieve respectful deaths in the future. Nurses can serve as spokespeople for the dying and advocates for change.

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References


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