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Cartoon by Jim Allen

American Association for Respiratory Care

Notes from the Editor:

Disability or Limitation?

by David W. Chang, EdD, RRT

As I was sitting in the waiting area of a local physical therapy department recently, I couldn't help but notice many individuals with different types of physical limitations. This observation reminds me of a legal case involving a nursing program's dismissal of a student who failed coursework on two occasions and failed to participate in counseling. The student claimed that she was perceived as disabled and thus was entitled to special accommodations in the nursing program. The court eventually ruled in favor of the nursing program. But the legal maneuvers were lengthy and costly. Many individuals suffered and had to deal with the unnecessary mental anguish.

Our student population is becoming more non-traditional and diverse. It may be wise to include a statement in your respiratory care course syllabus that reflects your compliance with the Americans with Disabilities Act of 1990 and the Rehabilitation Act of 1973 (Section 504). The Office of Disability Services or a similar office at your institution should have this document on hand. (See sample compliance statement below.)

In a nutshell, the eventual actions taken by an institution should address these points outlined by the Office for Civil Rights: The educational institution should (1) make every effort to provide reasonable accommodations to allow student participation in the program, (2) provide students with a notice of the standards, (3) supply the student with an explanation of how the student fails to meet the standards,

and (4) offer a reasonable opportunity to modify the behavior or participate in counseling so that the student can comply with reasonable standards of conduct.

As educators, we certainly do not wish to exclude any student (with or without physical or mental impairments) who shows the desire and has the ability to learn and succeed in a health profession. The compliance statement helps to provide equal access to those persons who can meet the standards of care. At the same time, the well-being of our patients is protected by limiting the participation in our programs of those persons (with or without physical or mental impairments) who cannot meet the same standards.

Sample ADA Compliance Statement

If you have a documented disability as described by the Rehabilitation Act of 1973 (Section 504) and Americans with Disabilities Act of 1990 (ADA), you may be eligible to receive accommodations to assist in programmatic and physical accessibility. We recommend that you contact the Office of Disability Services in _____ Hall, Room ____ or call _____. The Office of Disability Services can assist you and your instructor in formulating a reasonable accommodation plan. Course requirements will not be waived but accommodations may be made to assist you to meet the requirements. Technical support may also be available to meet your specific need. ■

1998/99 Calendar Deadline

March 13, 1999 PPS Exam.....	November 1, 1998
International Respiratory Congress (Atlanta)	November 7-10, 1998
Respiratory Care Education Annual Paper.....	December 1, 1998
March 13, 1999 CRTT Exam.....	January 1, 1999
June 5, 1999 RRT Exam.....	February 1, 1999
June 5, 1999 CPFT Exam.....	April 1, 1999
December 4, 1999 RPFTEExam	September, 1999

1998 ARCF Award-Winning Education Papers

The American Respiratory Care Foundation (ARCF) offers many education recognition awards to students in respiratory therapy programs. Each of these awards requires the applicant to submit a paper on a respiratory therapy-related topic.

In order to help promote these awards, we are featuring the winning papers in the Bulletin over the course of the year. The following two papers, both of which address the issue of death and dying, are the first of our 1998 award winners. Faculty members

are asked to encourage their students to submit their papers for consideration of these awards. For questions about ARCF programs and activities, call (972) 243-2272. ■

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Practical advice for the respiratory care practitioner dealing with the terminal situation

A caring touch can often be more eloquent than words.

Editor's Note: Laura Ziegler of Perham, MN, is a student in the respiratory care program at North Dakota State University. She will be recognized as the recipient of the Robert M. Lawrence, MD Education Recognition Award at the International Respiratory Congress in November.

Even with all of the medical advances of modern technology, one thing remains: we all eventually die. This fact, coupled with the increase in institutionalized deaths in this century, ensures that health care professionals who work directly in patient care are certain to deal with terminal situations. Statistics confirm that respiratory therapists will interact with terminal patients. According to the Statistical Abstract of the United States 1997, the three leading causes of death in the United States are major cardiovascular diseases, malignancies (with those of the respiratory and thoracic organs ranked first), and chronic obstructive pulmonary disease. (1) The demand for respiratory care is evident in each of these categories, and the need for adequately prepared practitioners becomes obvious.

Therapists often question how to best approach the terminal patient and his/her family. In our death-denying society, we receive little instruction as to what the needs of the dying truly are. Some practical, applicable advice on a positive approach toward terminal patients and their families could facilitate improved patient care and communication during a difficult time for all involved. To the extent that the terminal situation creates stressful

working conditions, these tools could also serve to lessen occupational burnout for therapists. With these benefits in mind, what does the research tell us concerning the approach most helpful in the terminal situation?

How to approach the terminal patient

The therapist's approach to the terminal situation is of great importance to the patient. At a time when technology has allowed health care providers to increasingly distance themselves from dying patients, we need to be increasingly aware of the patient's need for socialization. (2) While we may assume that pain tops the list of patients' fears about dying, Geppert reveals that psychosocial issues such as being a burden to others and loss of relationships are most prominent. These fears cannot be addressed if those responsible for the care of the dying patient distance themselves and focus only on the scientific aspects of care.

Callanan offers some practical advice for increasing communication with the dying patient. (3) First, we should consider our own feelings about death and why we feel this way. As care providers, we need to separate our fears from our care if we are to provide an accepting atmosphere for those facing life's end. It may seem an obvious fact that our patients' fears and priorities may not equal our own, but in the intricacies of human emotions this fact can easily be obscured. Simply stated, focus on their needs rather than your own.

Next, we are prompted to understand the patient and how he/she copes. (3) Each patient is a unique

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individual with different ways of coping during stressful situations. Joel agrees, as she states that we sometimes overlook the fact that a person’s death is as unique as his or her life. (4) Just as the research has demonstrated the inability of “stages” to adequately encompass each and every dying situation, we also need to realize there are no right or wrong patient responses. One person may need quiet time for reflection while another requires social stimulation. (3) The ability to understand and adapt to these differences can mean the difference between caring, insightful interactions and senseless misunderstandings.

Our third task is opening the door to meaningful discussion. (3) Some possible strategies are to describe what we see, perhaps by saying how the patient looks today and asking how he or she feels, to clarify our concern verbally. Don’t simply assume they will know you care; to acknowledge their struggle, or when unsure how to approach the situation, a caring touch can often be more eloquent than words. In our efforts to open communication, it is important to remember that timing is key — communication should be on their terms, not our schedule. Once the lines of communication have opened, we should answer difficult questions directly and honestly, and be willing to listen and help if we can. These efforts can facilitate the emergence of a cooperative, nurturing atmosphere for all involved in the terminal situation.

Don’t deny denial

Once we have begun to interact with our patients, we may meet with responses that run contrary to logic. Denial, defined as an extreme response in which one attempts to cope with danger or loss by ignoring important features of reality, is not necessarily unhealthy. (5) Denial has gained a negative connotation, but it can definitely produce some positive therapeutic results. (6) Ranging from maintaining morale to assisting in tolerating an intolerable situation, these benefits should not be minimized. Smith has revealed that patients with high levels of denial had fewer emotional problems in work, personal, and social activities than patients with low levels of denial. While the patient in denial may be difficult for the rational therapist to accept, it remains our

responsibility to support reactions that help the patient cope. We must realize that they are important to the patient’s survival in the face of death and do not imply weakness. To refuse the dying patient’s right to utilize denial is an abuse of power by those who have pledged to care for and respect individuals in a vulnerable position. Corr agrees and states that the insistence that one ought to cope with dying in a particular way risks disempowering the very people who most need empowerment. (7) It is the secure, self-assured therapist who has the ability to provide quality care for each and every patient, regardless of the circumstances.

The patient calls the shots

It should be commonly understood that we respect the wishes of our patients regarding their treatments and activities of daily living. In our cure-driven medical system, this basic right sometimes yields to our desires for a good outcome. It may be difficult for medical professionals to come to terms with the fact that, at a certain point, living becomes prolongation of dying for our terminal patients. (8) We may become so absorbed in the quest for “cure” that our duty to “care” is overlooked. Research has shown that high technology cure-based treatments do not necessarily lead to better outcomes than low-technology, family-centered approaches to the care of chronically critically ill patients. (9) At some point in most terminal illnesses, the change from cure to care takes place. This decision should be left with the patient as much as possible.

This principle carries over into decisions regarding daily activities as well. The tasks, or coping work of the terminal patient, should remain his or her choice. (7) While we concern ourselves with the technical aspects of care for eight or 12 hours a day, our patients are living with dying. But no one is dying 24 hours a day. What we, as caretakers, may feel is appropriate and necessary at a certain point in time may not be of primary concern to our patient. It is important that we relinquish control of daily choices to our patients as much as possible. In our quest to support our patients as individuals, we need to be aware that autonomy is supported to the degree that others value the uniqueness of the individual in question. We may need

occasional reminding that there is much that seems to be and truly is out of control in dying, but if the individual can make choices about which tasks will be undertaken, then the individual has not lost all influence over this important process.

Dealing with the family

Although the end of life may seem a blessing after a long torturous struggle, the family has much left to deal with. Our care for the patient may have ended, but how we approach his or her family can affect the grieving process. According to the literature, there are several things we can do to make this difficult time more bearable for survivors. First, Range, Walston, and Pollard prompt us to choose our comments carefully. (10) Research into which comments are helpful to recently bereaved survivors reveals that the most helpful are, “I’m here if you need someone to talk to,” and “if there is anything I can do, please let me know.” The evidence also shows that the least helpful comments are compliments on the funeral home’s job; questions about foreknowledge of the death, the deceased’s pain, or how the death happened; remarks about the death’s suddenness or life’s unfairness; or permission for the bereaved person to be angry at God. As caregivers, we would be well-advised to question our motives when we communicate with newly bereaved survivors. Our goals should center around comforting others rather than satisfying our curiosity.

Several other strategies exist to assist families who find themselves recently bereaved. Williams and Frangesch summarize the results of a Midwest hospital’s attempt to meet the needs of the grieving survivor at the time of death notification and for a period of two months after the death. (11) They remind us that survivors are often confronted with the news of death in the unfamiliar setting of the hospital. In this situation, it is up to the health care professional to assist the family in any way possible. Survivors reported several beneficial strategies, such as providing a private room for the family, communicating about the death in clear language, giving comfort measures, providing reassurance regarding medical treatment, facilitating viewing of the body, acknowledging the need to

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mourn, providing a follow-up name and number, and showing care and concern. Once again, we need to be reminded that our work is not finished when death has been pronounced. These efforts may seem inconsequential at a time when emotions know no bounds and survivors face many decisions. But if our attempts can ease the burden even slightly, they will allow those under great stress to focus their energy on more important matters. Overall, we can make a difference, as the literature demonstrates that individuals who perceive social support to be of high quality seem to feel less overwhelmed by the loss, less lonely, and better able to cope.

Preparation for the terminal experience

Much of the literature in the area of death and dying focuses on education and support for those who find themselves frequently facing the terminal situation. The effect of an increase in educational level displays itself in the study by Carr and Merriman, which utilized the death attitude index (DAI) to display the individual comfort level with death issues and care of dying patients. (12) Their study revealed that level of education was the one independent variable that correlated best with scores on the DAI. They discovered that those caregivers with lower educational levels, such as nurses aides, had the lowest death attitude scores and displayed the most discomfort with death and dying. While it may not be practical to expect that all health care professionals go through extensive training to reduce their death anxiety, there may be practical ways to assist those in contact with the terminally ill. Even a brief seminar on coping with the terminal situation might be of benefit. Carr and Merriman discovered that another factor that correlated with higher scores on the DAI was attendance at a seminar on death and dying or other training in the area. Their research showed that those individuals attending one or more seminars dealing with death and dying displayed a higher mean score than those who had not participated in this kind of educational activity. Considering the fact that most, if not all, health care professionals are required to participate in some form of continuing education each year to maintain their credentials, it does not

seem an impossibility to incorporate some form of death education.

Another form of education proposed by Coffman and Coffman is that of behavioral reversal. (13) This activity presents a more introspective approach to the death education experience, as students are asked to rehearse their own death. Through this creative exercise we fantasize the circumstances surrounding our death, which can ultimately make the performance of life more meaningful and the drama of death perhaps softer and more acceptable. In a society which seldom allows us to rehearse or play out the possibility of death, this activity could help practitioners who need sympathetic understanding of the dying process in their routine interactions with the dying and bereaved to gain some personal perspective. It may not always be possible to realistically “put ourselves in their shoes” when it comes to understanding the terminal patient. But we can try to reflect on their circumstances through mental stimulation such as behavioral reversal.

Personal support and advice for the respiratory therapist

All of the preparation and education possible may not be enough to prevent the stress which accompanies losing our battle to save those in our care. It remains a commonly accepted fact that those who work with the terminally ill have been successful in meeting the needs of the patients — but often at their own expense. (14) Often labeled “burnout” (the process whereby health care workers become exhausted, detached, and feel less personal accomplishment), the adverse affects of dealing with terminally ill patients need to be addressed on an individual and institutional basis. While many of the strains on health care workers can be considered external stressors, whose remediation requires action through the administrative channels, others can be addressed on a personal level. Among the suggestions offered by Riordan and Saltzer we find the request that an attempt be made to cultivate an internal locus of control.

Included in this task are assuming responsibility for choosing to work with the dying and honestly reviewing the reasons for this choice. Do we have personal reasons for our occupational choice? Are our goals in caring

for the terminally ill realistic? Riordan and Saltzer also suggest adoption of a team approach to our care. This can provide both physical and emotional support, along with the flexibility needed to work in such an emotionally charged field. If possible, the utilization of staff support groups and self-care wellness programs can prove beneficial as well. We are also asked to take a personal inventory of time spent weekly in stress-reducing activities. When a good share of our waking hours are spent giving to others in the emotionally stressful environment of health care, it becomes essential that we give back to ourselves if we are to remain beneficial to others.

Puckett provides us with some specific examples of strategies that have been reported as helpful by nurses working with the terminally ill. (15) She furnishes some practical, individual coping strategies, such as sharing our thoughts, writing letters to the patient who died, making time for enjoyable activities, exercising regularly, treating ourselves to little extras, and working through our grief gradually. In our fast-paced society, many of us can benefit from these suggestions. The therapist dealing with the terminal situation on a regular basis may require some extra support to continue as an effective part of the health care team.

Those of us choosing to pursue a career in medicine must be prepared to sacrifice for those in our care. These sacrifices may be physical, mental, and/or emotional in nature. Anything that we can do to reduce these strains should enable us to provide more sympathetic, understanding care to our patients. This paper has attempted to provide some suggestions from the literature for a more successful approach to the terminal situation. It is not my suggestion that every respiratory therapist adopt every strategy offered. Each person approaches the terminal situation with a unique history and personality. These individualities provide the wide array of talents needed in medicine. Along with these talents come individual weakness. The majority of respiratory therapists require support, advice, and/or consultation on occasion. The terminal situation often provides challenges that may require such support. Perhaps if we understand some practical strategies, our efforts in palliative care can reach

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our patients in such a thoughtful way as to gain the maximum benefits possible. After all, is it not our goal to provide the best care possible to our patients? If so, an approach to terminal patients which allows them comfort and dignity while reducing our anxiety should culminate in a situation that provides excellent care to all concerned.

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A discussion of euthanasia and its implications on health care

by Edgar F. Mahinay

A patient's right to die, as his/her right to live, is an important claim that cannot be disregarded.

Editor's Note: Edgar F. Mahinay of Jackson Heights, NY, is a student in the ventilatory care program at New York University. He will be recognized as the recipient of the Jimmy A. Young Memorial Education Recognition Award at the International Respiratory Congress in November.

It would seem that for a health care practitioner (HCP) working under the Hippocratic oath, the idea of euthanasia could not even be a consideration. Unfortunately, this is not the case in today's society. The idea that a person who has dedicated him/herself to the cause of preserving life and relieving another's suffering could assist in someone's death seems almost unscrupulous and hypocritical. Even so, this contradiction exists. It exists when a HCP stops feeding a patient, or ends any form of treatment to a patient, or "terminally weans" a patient off a mechanical ventilator (by reducing settings such as ventilatory

rate or the fraction of inspired oxygen).

Of course, these actions can only be performed with the consent of the patient or the patient's family, or if brain death has occurred with no possibility of recovery. Patients who belong in this category must be in one of several states: terminally ill, brain dead, or able to recover but with a severely reduced quality of life. Still, even under these circumstances, according to the Hippocratic oath HCPs are forbidden from causing harm or death by way of their actions.

It seems contradictory, but by prolonging the life of a patient who may be suffering greatly from a terminal illness, a HCP is both following and opposing the Hippocratic oath. By treating this patient, thereby prolonging his/her life, the oath is sustained, but by allowing the patient to suffer, the oath is contradicted. It is a moral dilemma that impacts HCPs, the patient, and his/her family, and has implications for society as well. In this essay, I hope to show both sides of the debate and how decisions made by HCPs and patients and their families can affect and shape what is generally considered morally and ethically correct by society.

A patient's right to die, as his/her right to live, is an important claim that cannot be disregarded. When Karen Quinlan slipped into a coma in 1975, she was placed on a ventilator. Then began a time of waiting. (6) Her prognosis was bleak, with doctors stating that she would never wake up from her comatose state because of excessive damage to her brain. Following days of discussion, the Quinlans requested that her life support machines be turned off and she be allowed to pass away. In this case, the Hippocratic oath the HCPs had taken came through, and they refused.

When the case went to court, it was argued that Karen had a "right to die," and extraordinary means to preserve her life to the last possible moment were not necessary. In March of 1985, the Quinlan family finally won the right to turn off Karen's ventilator. However, contrary to what everyone thought would happen, Karen was able to survive without it, and died finally in 1996. Her case brought national attention to the problem of having to decide whether extraordinary means should be applied when the patient is

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in a permanent unconscious state with no hope of recovery or brain activity.

Even though the decision to allow the patient to die by passive means is much less morally conflicting than actually performing some action to bring about death (such as shooting someone with a gun or poisoning someone), the feelings of guilt and responsibility are still there for the HCP and the patient's family. Whether or not someone dies, either on or off a mechanical ventilator, the real question that needs to be addressed is whether that person who shuts off the life-support, or discontinues feeding, or stops treatments is committing murder or just allowing a terminally ill or comatose patient a quick, merciful, and painless death. These cases are not clear cut, as evidenced by the case of Karen Quinlan, whose death was neither murder nor a quick merciful death. By surviving off a ventilator for ten more years, her suffering continued (contrary to what the family wanted) and the HCPs involved with her case could not be considered murderers (since she did not die as a direct result of being denied life support).

So who was right in this case? The doctors, nurses, and other HCPs did not want to violate their oath of preserving life, and the family of the patient did not want to continue her suffering knowing that she would never be able to live a normal life again. It seems that from whatever angle one views this case, all parties were trying to do what was morally and/or ethically right in their own minds. There should be a standard of practice that can be expected from HCPs and hospitals when such a situation does arise so that patients, families, and HCPs will know what to do. Measures should be enacted to ensure that this standard is followed through.

From the patient's point of view, a right to autonomy and a right to make his/her own decisions concerning health care is important and is upheld by the law. But for doctors, nurses, and other HCPs, it is important to use knowledge and skills to try and keep patients alive. What happens when the patient is terminally ill and is suffering due to that illness and looks to assisted suicide as an answer rather than treatments that will simply prolong suffering or the time to eventual death? Assisted suicide can seem like a form of passive death, but it really brings

the HCP close to the edge of assisted murder.

In my view, giving someone the knowledge and means of killing him/herself resembles assisted murder more than assisted suicide. It resembles murder because, like giving someone a loaded gun, the method of suicide serves one purpose: the death of someone for whom you have sworn to keep alive and relieve suffering. Some may argue that assisted suicide is more like the quick, painless, and merciful death (as in terminal weaning), but in this case the HCP is not allowing the patient to die on his/her own; he/she is actively assisting in the death. In my mind, the active role played by the HCP removes him/her from the role of healer to the role of murderer. As reiterated by other writers over and over again, if one can choose to allow someone to die because of some illness or debilitating disease, then why not because they are elderly or handicapped? (5) A bridge — any kind of bridge that would lead from assisted suicide to euthanasia — would lead to the killing of individuals who are different in one way or another. This would seriously undermine the morality of society as a whole by justifying killing someone due to one reason or another. As long as a "why?" could be answered, the action could be justified.

Only when a patient wishes to end extraordinary measures of life support does the Hippocratic oath and the law remain intact. Here the patient is, in a way, almost refusing treatment. This he/she can do by right. But when a HCP actively aids in the patient's death, then that person has violated the oath, as well as the law in 35 states (3). For families, it is a question of what they feel is best for their ill member. If prolonged suffering is at issue, then that family must decide whether allowing extraordinary life-support measures is in their family member's best interests. If it is not, then I feel they should have the right to decide to end those extra measures and allow the suffering to pass away naturally. Not only can a lengthy hospital stay serve no further good to the patient, but the emotional strain on that patient's family would also be tremendous.

HCPs should not be allowed to interfere in this process unless they have medical and scientific reason to believe that recovery is possible. As a society, we have a moral obligation to

insure that every life is given the full chance to live and exist in the world, and for HCPs that moral obligation comes in the form of an oath that they must swear to and be held responsible for at their jobs. By assisting another member of society to commit suicide, the message that this life was not worth fighting for is sent out to others. I believe that every life is worth at least a chance and has the possibility of offering back much more.

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