AIDS, Nursing, and Physician-Assisted Suicide: Part 2

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Nurses who work in HIV/AIDS care often hold conflicting views from each other about appropriate nursing roles in relation to physician-assisted suicide. Regardless of whether the individual nurse supports or opposes physician-assisted suicide, nurses in HIV/AIDS care need to have a broad knowledge base of the legal and ethical issues related to physician-assisted suicide. This article has as its major purpose to provide nurses with the knowledge base they need to assist them in their work in clinical practice, education, policy development, and research.

Key words: HIV/AIDS, nursing, physician-assisted suicide, palliative care

The overall purpose of this article is to provide a knowledge base about physician-assisted suicide (PAS) that will be useful to nurses in their work and communities. Part 1 presented a general introduction to the issue of assisted dying. In writing this article, the author assumed that many individual nurses have already taken a moral stand either pro or con PAS. Rather than try to influence or support either stand, this article presents information to enhance the nurse’s knowledge so that nursing actions are informed actions. In Part 1, background information described major legal and ethical issues related to PAS, and a list of definitions was included.

Part 2 of this article discusses the safeguards usually considered in discussions of PAS: terminal illness, competency/capacity, voluntariness, palliative care, depression, quality of life/suffering, durability of request, witnesses, and public reports. Issues that nurses might want to consider in working toward policy or political change have been included. Special circumstances and populations discussed include the following topics: (a) when things go wrong, (b) people with disabilities, and (c) families and children. Finally, the author considers nursing roles/ responsibilities where PAS is legal.

Safeguards

Most proponents of PAS believe that formal legalization will reduce suffering by allowing individuals choices that would enable them to avoid a depersonalized, expensive, and uncomfortable death, while also providing sufficient safeguards to prevent abuse or exploitation. In the Netherlands and Oregon, advocates for PAS proclaim they have developed adequate safeguards, but others disagree. Developing adequate safeguards is an aspiration that has been just out of reach for many reasons. Some argue that adequate safeguards are impossible because the very guidelines that are proposed to provide safeguards open the door to undesirable results, such as opening the back door to euthanasia (Callahan & White, 1996).

Some impediments occur in each of the safeguards, such as imprecise definitions, cumbersome procedures, and uneven levels of clinical ability among physicians and other health care staff. Proponents struggle...
to overcome these impediments and advocate that PAS should be restricted to terminally ill, competent adults whose quality of life is unacceptable because of distressing symptoms.

On the other hand, the current status in most states—assisted suicide is a crime—provides no safeguards and leaves patients and their families with no recourse or protection from abuse. In the United States, most legal and clinical discussions about safeguards occur within the context of terminal illness, competence/capacity, voluntariness, palliative care, depression, quality of life/suffering, durability of request, and witnesses. Considerations and concerns about these safeguards will be discussed.

**Terminal Illness**

People often are confused about what constitutes a terminal illness. Many illnesses exist that are both chronic in nature and incurable, but they are not generally considered terminal. Multiple sclerosis and diabetes mellitus qualify as chronic, incurable illnesses, but neither is considered terminal, although either may eventually lead to complications that cause death. Some terminal illnesses progress slowly and may eventually result in a person’s death, but doctors cannot predict the time of death. For example, many cardiac conditions are identified as potentially or probably terminal, but the physician may only be able to say that this illness will likely cause the individual’s death at some time in the future, as is also true for some very slowly progressing cancers.

HIV/AIDS is a chronic, life-threatening illness that has no cure. Until the advent of recent combination therapies, HIV/AIDS was a progressive illness with a trajectory that, with few exceptions, could be charted from exposure to death. Now, existing and promising therapies are reconfiguring this trajectory, although the new therapies have not benefitted all HIV-infected individuals and are too expensive for others. HIV/AIDS is still viewed as a terminal illness despite the declining death rate and the longer time from exposure to HIV until death, secondary to more effective preventive and treatment regimes. Diagnosis of a terminal illness can be made at any point along the trajectory, and the individual being diagnosed may actually be 20 years or more away from his or her death at the time of disease detection (Saunders & McCorkle, 1985). This situation can also be true for other illnesses regarded as terminal. Nurses need to differentiate a terminal illness from a terminal phase of illness when considering PAS safeguards.

Many proponents of PAS believe that eligibility for PAS should be extended to all with a terminal illness, regardless of the trajectory of that illness or where the patient is within that trajectory. Yet, other proponents argue for greater precision and limits within the safeguard of terminal illness. For example, rather than having a terminal illness per se as a qualification for eligibility for PAS, these proponents ask for PAS to be limited to the terminal phase of an illness. Still, the question of defining the terminal phase remains.

Although it is tempting to identify a time frame to operationalize the terminal phase of an illness, this approach has many pitfalls. Some writings include the qualifier, “no more than 4 to 6 months to live,” as a safeguard for a person with a terminal illness. Predicting how long a person will live in months, weeks, or days is more akin to crystal-ball gazing than to radiographic or biopsy diagnosis. Recent efforts to develop a statistical model that will improve the prognostication of survival time for seriously ill individuals are promising for the future (Lynn, 1997).

Years ago, Pattison (1977) defined the terminal phase of an illness as that part of the living-dying interval when no further medical intervention was available to halt the pathological progression of the disease, and only palliative care remained. Clinicians are more likely to agree that an individual patient is in the terminal phase of an illness than to predict how much longer the person has to live. Still, many seek to link terminal illness with a time frame, despite the difficulties inherent in that stance.

Terminal illness, and not incurable illness, continues to be the safeguard with the strongest support among clinicians, the public, and legislators despite confusion and other pitfalls. A person with a terminal illness who seeks PAS is perceived by most—professionals, legislators, and the lay public—as simply making an inevitable death happen sooner within an already acknowledged shortened life trajectory. The context, terminal illness, already includes the distinct process of dying.
Although physicians cannot accurately specify when someone will die, they can correctly determine that an individual’s illness is terminal or life-threatening.

**Competence/Capacity**

Strictly speaking, competence is a legal concept, not a medical one. Traditionally, an adult has been considered competent unless there is some reason to question the person’s ability to understand information sufficiently for decision making. Technically, only the courts can declare a person competent or incompetent, whereas *capacity* is the term used in making this determination in medical settings, outside of the courtroom (The Hastings Center, 1987). Youths who are under the legal age are considered incompetent to make their own decisions, but some state laws have been modified to let adolescents make decisions about selected health care issues, such as contraception and abortion, before they reach the age of 18. Generally, when current laws were changed to lower the age of independent decision making, it was in the service of encouraging adolescents to seek help for health problems they might otherwise avoid if they had to turn to their parents first (Muscari, 1998). For youths under the age of 18 who are in a terminal phase of HIV/AIDS, parents would probably hold the decision-making authority about end-of-life decisions under current law and practices.

Competence, or capacity, when assessed, is actually an assessment that the person is not incompetent (Callahan & White, 1996). No standard test or procedure is available to use in determining individual competence. Generally, no agreement exists on the circumstances that should call into question whether the individual has the capacity to make decisions and to understand the consequences of those decisions. Complicating the situation further is that recently, the concept of capacity has been viewed as relational; that is, capacity has levels, and level should be matched to the complexity and gravity of the decision to be made (Callahan & White, 1996). Within the context of relational capacity, then, a demented person might decide whether to have milk or tea with dinner but be unable to choose one combination therapy for AIDS over another. Making the concept even more difficult is the fact that individual capacity may fluctuate over time, independent of the complexity and gravity of the decision per se; that is, an individual may seem alert and clear in the morning but have difficulty thinking clearly in the evening.

The Oregon model of PAS provides the safeguard of determining competence when either the treating or consulting physician believes there is reason to question the patient’s decision-making capacity. Then, the physician refers the patient for psychological evaluation specifically for impaired judgment, not for depression. This feature of the Oregon law safeguard may be too narrowly written, and people with treatable depression may seek and receive access to PAS when their judgment is clouded by depression. The referral for assessment of competence should not involve the patient in unduly burdensome procedures, either in the length of time needed for the assessment or in unwieldy assessment procedures. The consultant assessing the patient’s competence should remember that this terminally ill patient usually has limited energy and time.

**Voluntariness**

The safeguard of voluntariness is intended to assure that the individual seeking PAS is doing so of his or her own free will, without coercion or manipulation. Voluntariness generally occurs when an individual is competent to make the request and/or has the capacity to understand the full implications of requesting PAS. Many subtle pressures exist for the person who is terminally ill, and subtle pressures themselves can compromise the patient’s voluntary status in seeking PAS. These pressures are diverse, such as avoiding the financial burden of a costly illness over time, protecting others from the suffering inherent in seeing the continued debilitation and distress of a loved one, and avoiding personal discomfort (Isaacs & Knickman, 1997). Subtle pressures can emerge from real circumstances the person is already facing or from unreal fears, such as the fear of being an undue burden on others when others do not feel the patient is a burden. The sensitive nurse will explore these concerns carefully with the patient. These subtle pressures should be discussed openly, rather than leaving the patient to struggle with these concerns alone, without the opportunity
to validate his or her concerns. Callahan and White (1996, p. 41) pointed out that none of the proposed laws they reviewed defined voluntariness. Voluntariness refers to the individual’s making choices that are free from coercion and manipulation (Bandman & Bandman, 1995; Beauchamp, 1994). Implied in free choice is having adequate information related to the specific situation, as voluntariness is weighed within a particular context. Within a situation, then, the hallmark of voluntariness is to be free from pressure from others to choose a particular course of action.

Palliative Care

The goal of palliative care is to make the person as comfortable as possible and to maintain an optimal quality of life, that is, to give the person adequate care to relieve distressing symptoms. This concept is also more difficult than it seems on the surface. Some people argue that medicine has the capacity to relieve all pain, dyspnea, diarrhea, and other distressing symptoms. The truth is that neither the symptom nor its distress can be adequately relieved for all patients. Although the capacity to relieve many symptoms has improved, even the best practitioner working in the best of circumstances cannot relieve all distress, including pain. The art of pain relief involves balancing the pain relief with unwanted symptoms, such as sedation or constipation. The issue, however, is more complex than technical competency to relieve symptom distress.

Most physicians and nurses do not use the knowledge available to them in managing pain and other distressing symptoms (Holzemer, Henry, & Reilly, 1998; Ventafridda, 1994). In one large-scale study (n = 9,105) of very sick hospitalized patients, researchers found that one fourth of the patients experienced serious pain during hospitalization, and a large percentage of patients who died experienced moderate to severe pain (Lynn, 1997). Despite available studies arguing to the contrary, many physicians and nurses refuse to administer adequate doses of narcotics to relieve pain because they are fearful of causing addiction, even among terminally ill patients. Intensive symptom management is at the heart of palliative care (Bloomer, 1998).

Palliative care is beginning to emerge as a specialty in the United States, as universities have begun to offer graduate programs in palliative care. Certification examinations in palliative care are also being developed. Although palliative care is just emerging as a specialty for physicians and nurses in the United States, palliative medicine has been a specialty since 1987 in the United Kingdom, where physicians receive a 4-year rigorous course of study. Certification as palliative care specialists should be available to all health care professionals (nurses, physicians, etc.) who contribute greatly to this important area of care.

Some argue that PAS should be offered only to individuals who have received adequate palliative care, but they admit that without standards and qualified, accessible practitioners, calling for this rigid application of a standard as a safeguard is a futile practice. Others argue that PAS should not depend on access to palliative care (E.W.D. Young et al., 1997). At the center of this discussion is the belief that individuals who have distress from symptoms that can be adequately managed ought to have relief from the symptoms without having to resort to death. At the same time, others argue that a person should be able to seek PAS whether or not palliative care is available. The argument, then, has been advanced from both directions: No one should be coerced into seeking PAS because he or she lacks access to adequate palliative care, and no one should be prevented from seeking PAS because he or she does have access to, and does use, adequate palliative care (E.W.D. Young et al., 1997).

Allowing patients to die naturally or from PAS does not replace society’s obligation to relieve symptoms and suffering. Access to adequate palliative care should be the cornerstone of end-of-life care for any society, and PAS advocates and opponents easily can unite in the search for access to adequate palliative care.

Depression

Perhaps some health professionals continue to believe that suicide is always intertwined with mental illness, most notably depression. When one is not personally involved in a terminal illness, it seems natural to believe that the terminally ill person must be depressed. Many people do develop transitional
depressed moods episodically throughout their illness experiences, but being terminally ill and/or thinking about suicide are not always linked with either a depressed mood or a depression diagnosis.

Three issues are relevant here. First, professionals should not assume depression exists because of an individual’s circumstances without determining how a patient is responding to those circumstances. Instead of assuming, assess the individual for depression. Second, depression can cloud a person’s thinking and reduce the capacity for clearly weighing the consequences of PAS. Ruling out depression is an important component of the mental status assessment that also establishes competence. Third, depression is a painful and treatable disorder. Depression that meets formal diagnostic criteria of major depression is not the same as a transient depressed mood or sadness. Diagnosing depression in a person who has a chronic, life-threatening illness can be difficult because some of the symptoms of chronic physical illness and depression overlap, such as decreased appetite, loss of weight, altered sleep patterns, and fatigue or lack of energy (Valente & Saunders, 1997a, 1997b, 1998).

Quality of Life/Suffering

In his classic article, May (1978) wrote, “neither physicians nor the society at large ought to prize so highly the quality of life that they solve the problem of suffering by eliminating the sufferer” (p. 116). The current movement related to end-of-life care, rights, and responsibilities has pitted suffering and reduced quality of life against the obligation to continue life. Although relieving suffering has been a major focus of nursing for many years, only recently have there been attempts to understand suffering conceptually and clinically (Kahn & Steeves, 1996; Saunders, 1996; Travelbee, 1971). On the other hand, quality of life has been a sustained focus of attention by nurses, social scientists, and other health care workers for several years.

Pain and suffering are different phenomena, not simply different words for the same distress, yet both are recognized as uncomfortable personal experiences (Cassell, 1982; Copp, 1990; Kahn & Steeves, 1986; Lindholm & Eriksson, 1993; Saunders, 1996; Spross, 1996). Suffering is a disharmony within the self that may be triggered by many sources, but it is a disharmony that is always linked to what matters to the person. Many aspects of HIV/AIDS have the potential to evoke or to intensify individual suffering, such as stigma from society’s negative reaction, the chronic nature of the disease, and its incurability and potential mortality (Saunders, 1996). Health care practitioners have well-developed guidelines and technical assistance available for relieving their patients’ pain and poor guidelines for relieving suffering. Regardless of the source of suffering, quality of life is directly related to the individual’s suffering. The personal experiences of suffering and quality of life are assessed by gathering data from the person experiencing the distress, rather than through observation by others.

Durability of Request

To ensure that the person’s request for PAS is not impulsive, most proposed laws have a waiting period. The other intent of this provision is to ensure that the person’s decision is voluntary and without undue influence from others. Oregon’s law requires a 15-day waiting period between the patient’s initial request and the physician’s writing the prescription for lethal doses of drugs (Callahan & White, 1996). Ideally, a duration of time that reflects voluntariness would also provide evidence of persistence in thinking consistent with values and lifestyle behaviors that supported the request for PAS. Because the person is terminally ill, durability of request often is restricted to a more limited time frame than would be the safeguard standard for judging durability for different purposes than seeking PAS.

Witnesses

Witnesses to any transaction dilute the privacy of the situation by adding another person to the equation, who is there to ensure that important elements of the transaction are followed. Ideally, witnesses should know the person requesting PAS so they can attest to personal characteristics that address competence and lack of coercion. These are difficult components to assess, however, so most witnesses can provide only superficial impressions, and their presence is limited to attesting that the individuals signed the document.
Witnesses usually must meet the criterion of not having a direct and personal interest in the person requesting PAS, such as being a benefactor of the estate. The physician who will provide the assistance is sometimes required to sign the request form as one witness, usually when another witness also is required. These are the witnessing safeguard considerations in laws that have been sought regarding PAS.

There is a larger concept of witnessing, however, which entails having someone who can carry forward the story of the event that is witnessed. This concept acknowledges that someone else is involved in the event who can recall to others, if needed, the story of the incident. In this sense, the family, friends, and health professionals who support the dying person through death are themselves witnesses, although not in the legal sense of ensuring that safeguards and protocols are followed.

## Public Reports

Adequate requirements for record keeping and reporting are necessary so that examination for potential abuses can be implemented. Trends in PAS can only be revealed through adequate reporting, so that indicators of the feared slippery-slope practices can be identified. Reporting relies on the willingness of the physician to reveal actions that have resulted from very private physician-patient interactions. Opponents of PAS argue that physicians will only report those actions that fully meet the criteria specified in the law and will not risk endangering themselves by reporting those practices that live in the gray areas. For example, a physician might be unwilling to report PAS for a person with AIDS-related dementia and will, instead, list that death as natural.

## Policy and Politics

Changing public opinion often precedes the process of creating or altering policies that guide formalization of practices through procedures, rules, regulations, and laws. Capturing public opinion is equally important when individuals or groups work to preserve existing policies and resulting procedures, rules, regulations, and laws. Nurses work to change policy at many levels, but most nurses will direct their actions toward those settings where they work and the communities in which they live. Many principles and strategies apply at all levels of policy actions, whether the scope of action is local, national, or international—only budgets, needed resources, and level of sophistication will change.

### Basic Considerations

#### Working Within Framework

Launching any successful project involves identifying the objectives, as well as the available and needed resources to accomplish the objectives. If individuals or groups are working from an established base, such as a tax-exempt organization, they will need to be very clear about the activities that they can legally engage in and those that are forbidden. For tax-exempt organizations, several sets of laws, such as the Internal Revenue Code, federal election laws, and state and election laws, will govern the parameters of activities legally sanctioned for raising funds and for accomplishing objectives (Colvin, 1995b).

#### Planning

Taking time early in the project to develop project milestones, timelines, personnel resources, and budget and to match resources with tasks will facilitate progress as well as helping the planning group to identify resources they need to locate or recruit. As more resources are needed for fund raising to support the group’s activities, fewer resources will be available to accomplish pivotal tasks. Even the most modest projects will need resources and planning to accomplish objectives. For example, changing a hospital policy may first require searching the literature. Nurses will identify studies that justify changing the hospital policy to support emerging practices according to current research. Nurses may also need to educate staff and administration about the practices supported in the literature to build support for the policy change. These activities may involve staff time and money for photocopying and developing materials to distribute.

Changing policies and laws requires organized and consistent action. Having a good cause alone will not result in changing policies and laws. Taking time to plan the project and to implement effective strategies...
will save time and money and may differentiate a successful campaign from an unsuccessful one. Resources are available to increase knowledge about lobbying, managing legal actions, fund raising, establishing a media program, and so on (Colvin, 1995a, 1995b; Fei & Colvin, 1995; Vallone, 1996a, 1996b). Most public libraries have references and guides for fund raising.

**Referendum, Policy, Legislation**

Changing a policy of a professional organization, such as the Association of Nurses in AIDS Care or the American Nurses Association (ANA), may be more challenging than changing a local agency policy, but both of these changes are smaller in scope and less complex than changing a law. Changes in laws are usually the result of working with legislators who are sympathetic to a cause or by qualifying an initiative for the voter ballot. Changing a law requires persistence and an unending fund of optimism and energy—and more than your fair share of luck. Occasionally, advocates will be fortunate to find an elected official who takes on their cause, but typically, they will need to remain active in lobbying many officials, providing research and assisting in other ways (Vallone, 1996a, 1996b). Many officials will be more receptive if advocates can demonstrate the timeliness of, and public receptivity to, this issue.

Experts are divided about whether it is better to change the law through existing legislative channels or to take the issue directly to the public through a voter referendum. Qualifying a referendum for the ballot requires obtaining a large number of qualified voter signatures. Either method can experience enactment delays because of court challenges that take years to progress through the court and appeals systems.

Several routes are available to those working for or against legalization of assisted dying. New laws can be created through the usual legislative process or by voter referendum. Proponents of PAS may strive to challenge in court existing laws that prohibit PAS, as was true in the two cases that were reviewed in 1997 by the U.S. Supreme Court (see discussion in Part 1). Many groups are formed and acting to change, defend, or challenge existing laws, and nurses may want to join an existing group, rather than attempting to start one of their own.

**Political Concerns in Shaping Public Policy**

Language is important in expressing ideas and in shaping ideas. Finding acceptable and accurate images to portray ideas is always challenging, especially for topics that are both sensitive and subject to misunderstanding or even distortion. Both sides of the argument related to assisted dying have been guilty of using terms and images that are designed to evoke fears and to garner public support (Callahan & White, 1996). Nurses will need to be vigilant in watching for distorted information in the press and for language that in and of itself puts a group on the defensive. Lee (1997) suggested that advocates should spend time and energy on media education and address their message to the middle third of the public, where opinions and stands are more malleable.

**Special Circumstances and Populations**

**When Things Go Wrong**

Literature sources are sparse about instances in which family or friends have been present when a terminally ill individual has attempted a planned suicide, only to discover that death did not occur. Many people use the discussions in *Final Exit* (Humphry, 1991) to provide guidelines for planning their suicide, but these discussions are not fail-safe and do not provide specific information for many situations. The patient who is alone after taking the combination of medications may have neither the energy nor the will to put the plastic bag over his or her face. Patients who have used a pain medication over time, such as morphine, will have developed a tolerance; yet, they are not advised about the tolerance effect when these medications are among the drugs used in assisted suicide.

In his study of assisted suicide, Jamison (1996, p. 224) found the most common thread among the stories of such relatives and friends was that they were thrust hastily from “merely being present” to “doing anything necessary” to bring about the death. Many factors contributed to this situation, such as inadequate research and planning about medication interactions.
and dosages, lack of knowledge about interactions between illness and medication, and a lack of sufficient time. People who had expected to simply be present during the suicide to prevent a loved one from dying alone found unexpectedly that the situation forced a role change from observer to participant. People reported being unprepared for this sudden change. The alternative was to fail their loved one and to have the loved one face unknown consequences of a failed overdose, such as living in a vegetative state, along with the added stigma of attempted suicide. Not having anticipated the possibility of having to change from a supportive presence to an active agent left the friend or relative in a precarious position, with many unanswered questions: Do I try to give more medication? Is it too late? Would he or she want me to cover the head with a plastic bag? Can I live with having killed a person I love? Will I be caught and tried for murder? Will I lose my professional license? Not only were these relatives or friends likely to be in a position unexamined in light of their personal beliefs and values, but if they acted to hasten the death, they were also now in legal jeopardy.

Friends and relatives described to Jamison (1996) how they removed evidence from the scene that would point to a death from any other means than natural ones, such as removing medication bottles or throwing away plastic bags and tape. Most denied personal regrets but continued to have vivid memories, discomfort, and images over the years. Friends and relatives who were hastily thrust into the position of actively participating in the death might take comfort that their actions did not betray another, but they were left to examine the possibility that they had betrayed themselves and their values.

No one has examined systematically the effect of “things going wrong” on the subsequent grief of relatives and friends. Grief is a time of sadness and loss, but it is also a time of seeking meaning in life. Carrying unresolved moral questions about one’s own behavior during the death of someone close cannot ease grief and discomfort. Future studies may tell us whether friends and relatives who were placed in these situations resolved their questions without prolonging their distress and grief.

**People With Disabilities**

People with AIDS are protected under the Americans With Disabilities Act (1990), but some would argue that the label disabled is itself a two-edged sword. Many people with AIDS have lived their lives as socially stigmatized individuals with many reasons to distrust the medical profession and feel rejected by society at large. Yet, many with HIV/AIDS have advocated for the right to control the time and nature of their dying through legally sanctioned access to euthanasia and PAS. Although Novick (1995) insisted that people with terminal illnesses have been left out of the dialogue about assisted death, many individuals and family members have written their views clearly, and those views are available in this ongoing dialogue (Madorsky, 1997; Rollin, 1985; Silvers, 1997). A vocal group of disabled Americans opposing current efforts that are under way to legalize PAS present compelling arguments: (a) distrust of health professionals to adequately value disabled peoples’ lives, (b) fear of being a burden, (c) increased pressure by social and economic forces to hasten the slippery slope for disabled people, (d) fear about the type of existence that would result from reduced pressure on society to offer the disabled lifestyle choices of dignity and satisfaction, and (e) current living conditions that foster compliance and lack of volition and also enhance the attractiveness of PAS (Madorsky, 1997; Silvers, 1997).

**Families and Children**

In the past 30 years, commercial and government organizations have published articles, books, and pamphlets focused on children and death (Blackburn, 1987; Grollman, 1970; National Institute of Mental Health, 1979; Simon, 1986). These publications have provided valuable insights to help parents talk with children about death and mourning, but they have not dealt with the child’s own death or guidelines for parents about continuing or stopping painful treatments associated with uncertain results.

More recently, publications have acknowledged special care needs and considerations for terminally ill children and their families (American Academy of Nursing, 1994; ANA, 1998; American Nurses...
Foundation, 1995: Association of Nurses in AIDS Care, 1996.). We know anecdotally that children with cancer or AIDS have asked their parents to stop chemotherapy and that parents have also made decisions to stop treatment on behalf of their children. As discussed earlier (see Safeguards, Competence), youths under the legal age are not considered competent to make their own medical decisions. Instead, parents decide what is best for children, explain the choices and consequences to the child, and, through discussion, gain the child’s cooperation and assent to the decision.

Until recently, our society perpetuated the myth that childhood was the golden age of innocence. As knowledge of family violence, child abuse, children’s being killed by their parents, and more recently, children’s killing other children has found its way into America’s awareness and conscience, parallel discussions of depression and suicide in childhood have not seemed so incongruous. Still, I have found no discussion of assisted dying that was extended to terminally ill children. If parents have participated in any actions to hasten their terminally ill children’s deaths other than withdrawing treatment, these actions have remained private and personal. Discussions of adequate palliative care for terminally and chronically ill individuals should not be limited to adults but must include palliative care for children and adolescents.

For adults, there is consensus that the patient, not the family, should be the primary decision maker about PAS. Family, as defined by patients, should be involved to the extent possible (E.W.D. Young et al., 1997). In the United States, many individuals with HIV/AIDS are also members of stigmatized groups, such as injection drug users and homosexual men, who have strained relationships with their families of origin. Optimally, patients and their families are involved and supportive of each other during a terminal illness, and patients should guide nurses in identifying people included in their family. The nurse should help patients gain access to resources that ensure that their designated families are granted legal status for inclusion in appropriate decisions.

Nursing Roles and Responsibilities
Where PAS Is Legal

General

Even in countries and states where PAS is legal or voluntary euthanasia is sanctioned (such as the Netherlands), the legal role of the nurse is often unclear. In the one situation in the Netherlands involving a nurse, rather than a physician, who was tried for euthanasia, the nurse was found guilty. I am not aware of any proposed referendum or legislation in the United States with language that includes health professionals besides physicians to provide others with the means for committing suicide. Besides actively providing the person with the means to commit suicide, however, there are many ways that nurses could choose to have an involved and active role in situations where PAS is legal (Oregon Nurses Association, 1995). A concern that needs to be addressed, however, is the possibility that nurses could be involved in a situation involving PAS without personal knowledge or choice. For example, if a nurse is working in an agency that allows PAS, the physician may have ordered lethal drugs for the patient without informing either the pharmacist or the nursing staff of the situation. Neither the pharmacist nor the nurse will have meaningful choices about their participation in PAS unless the communication among all team members is open.

Nursing Roles and Actions

Nurses can have a diversity of roles with patients and their families in situations involving PAS, both in direct care situations and in the larger arena of policy formation. Nurses have a strong tradition of advocacy for their patients, and PAS offers many opportunities for nurses to continue this active role. When nurses stay focused on the patient and his or her needs, advocacy efforts can help the patient progress through conflicts with family or other health care staff. The patient may perceive, correctly or incorrectly, pressures from either family or health care providers to make choices that are not consistent with what the patient actually wants to do.
Perhaps the least controversial role of nurses is educating patients, their families, and other health professionals about what is involved in a variety of choices. Nurses should not misuse the role of educator to pressure the patient or family into choices that come from personal stances. If one nurse cannot provide access to information from a variety of perspectives, then this role should be relinquished to another nurse who can be supportive of the patient and family across many issues and stances.

For those nurses who are comfortable with the dying patient and the stance that he or she has taken, the most comforting role might simply be “being present.” Being available to patients and their families during the time immediately before death requires patience and skill from nurses, and these attributes are even more pivotal when death is the result of suicide. Nurses who offer to stay with the patient and family in an acute care setting or in a hospice setting will have different supports available if the situation does not proceed as expected than nurses who stay with the patient and family in a private home. Nurses will want to take precautions to ensure that the role of supportive presence does not escalate into more active involvement if something goes wrong (Jamison, 1996). For that reason, nurses who are in a supportive presence role in a patient’s home should set very clear boundaries in advance and should make sure that the patient has someone else who will be there who can make decisions on his or her behalf.

Duty to Provide Care/Right to Refuse

Proponents and opponents agree that health professionals who do not believe in PAS should have the right to refuse to participate in actions related to PAS (Oregon Nurses Association, 1995; E.W.D. Young et al., 1997). In this, as in other situations, before withdrawing from the patient’s care, nurses have the obligation to refer the patient to other nurses to ensure the patient has continued access to competent care (Saunders, 1999). The patient and the designated family will need appropriate supportive nursing care and monitoring during the final stages of dying, whether the dying is being hastened by legally sanctioned actions of the patient or is the result of the natural progression of the illness.

Code of Ethics/ANA Position Paper

The ANA has been consistent in opposing nurse participation in assisted suicide and euthanasia, as such actions are believed to be in conflict with the Code for Nurses with Interpretive Statements (ANA, 1985, 1994; Ferrell & Rivera, 1996). These guidelines also provide nurses with a framework for caring for patients who are involved with end-of-life concerns and decisions.

Studies have indicated that nurses and other health professionals rarely support active euthanasia under any circumstance; yet, many do support PAS when the patient is terminally ill and has unrelieved suffering and an unacceptable quality of life (Coyle, 1992; Davis et al., 1993; Saunders & Valente, 1993; Valente, Saunders, & Grant, 1994; A. Young, Volker, Rieger, & Thorpe, 1993).

Summary

Most states continue to regard PAS as a crime, and therefore patients and their families are left with no recourse or protection from abuse. Most discussions of PAS eventually turn to the need for adequate safeguards and effective strategies for implementing them. For example, defining the terminal phase of a terminal illness has remained more art than science, despite some recent advances. The assessment of competence, or capacity, usually involves an evaluation that the person is not competent, and no standard test or procedure is available to assist with this. The safeguard of voluntariness is intended to assure that the motivation of individuals seeking PAS is not tainted by coercion. One of the most complex safeguards has been access to palliative care, and this point has been argued from both directions: No one should be coerced into seeking PAS by lacking access to palliative care, and no one should be prevented from seeking PAS because of access. Other safeguards discussed were depression, quality of life, durability of request, the role of witnesses, and the effect of public reporting. All safeguards have mixed inherent concerns that pose both conceptual and practical difficulties. Nurse activists use a variety of approaches to change policies or laws and to introduce new measures. Joining forces with...
existing groups and careful planning will help conserve resources needed to implement objectives. Of the many pivotal roles nurses have with patients and their families and PAS, perhaps the most pivotal roles is advocacy. Regardless of where any individual nurse stands on PAS, life, how we live it, and the nature of our dying matter to nurses. Nurses contribute to both the quality of life and the quality of dying.

Acknowledgment

This article was written in partial fulfillment of the resolution passed by the Association of Nurses in AIDS Care (ANAC) in 1997 on the Role of the HIV/AIDS Nurse in Assisted Suicide. In this resolution, ANAC encouraged its members to become active participants in policy and decision making and identified an organizational responsibility for ANAC to develop and provide information to its members to assist them to make informed choices about Physician Assisted Suicide (PAS). This article was developed at the request of ANAC to provide information about PAS. A copy of this resolution can be obtained by writing to the Association of Nurses in AIDS Care, 11250 Roger Bacon Drive, Suite 8, Reston, VA 20190-5202. ANAC appointed a Task Force on the Role of the HIV/AIDS Nurse in Assisted Suicide. Members were J. M. Saunders (Chair), R. K. Mallison (ANAC Board Liaison), D. Gleason-Morgan, M. Dunlap, D. Jones, and F. Lamendola. Early discussions of the task force helped to shape some of the ideas included in this article, but the author is solely responsible for the content.

Note

1. The following two recent publications provide an excellent discussion of issues germane to safeguards: N. A. Christakis’s 1999 Death Foretold (Guilford) and T. A. Preston’s 2000 Final Victory (Forum).

References


