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Some Personal Aspects of End-of-Life Decisionmaking

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Some Personal Aspects of End-of-Life Decisionmaking¹

JAMES L. WERTH, JR.*

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I. INTRODUCTION

As a psychologist and one of the few non-legal professionals invited to speak at the *University of Miami Law Review's* annual Symposium entitled "The Schiavo Case: Interdisciplinary Perspectives," I decided to emphasize some of the personal aspects of end-of-life situations and decisionmaking. In keeping with the original presentation, this Article employs a psychosocial framework to review a variety of topics, including advance directives, familial conflict, religious considerations, and multicultural influences, related to decisions near the end of life. Based on over fifteen years of professional and personal experience with dying individuals (primarily those with HIV), I use examples of people I have known to keep the humanity of dying persons and their loved ones at the center of attention. Because of my desire to focus on people instead of abstract concepts, I use the first person and talk about specific individuals to highlight certain points. Finally, when possible, I also incorporate relevant legal points and issues.

1. An earlier version of this Article was presented on February 18, 2006, as part of the *University of Miami Law Review's* annual Symposium entitled "The Schiavo Case: Interdisciplinary Perspectives."

* This Article is dedicated to the many ill and dying people I have known and with whom I have had the honor of working over the last fifteen years.

II. PSYCHOSOCIAL ISSUES

For the purposes of this Article, psychosocial issues include mental conditions such as clinical depression (not just being sad or blue but feeling so bad that suicide may seem like the only option), clinical anxiety disorders (such as Post-Traumatic Stress Disorder), dementia, and substance abuse.² Personal considerations that are not mental disorders are also included, such as autonomy, dignity, and spirituality.³ A final group of considerations include interpersonal and environmental issues, such as relationships with others and concerns about these relationships (such as fear of being a “burden”), as well as one’s cultural background and relationship to society.⁴

Research and anecdotal reports support the contention that psychosocial issues are among the most important determinants of quality of life during the end-of-life process for the dying person and his or her loved ones.⁵ These aspects often receive short shrift, however, because the focus tends to be on physical suffering. But rather than focusing on physical suffering alone, it is preferable to take a holistic, interdisciplinary approach.⁶ In order to balance the tendency to emphasize physical issues to the exclusion of other aspects of the dying process, below I discuss psychosocial aspects of end-of-life situations that warrant attention.

III. ADVANCE DIRECTIVES

I started counseling persons with HIV in 1991 before the medical miracles of the late 1990s. Although I stopped counting, I would guess that over one hundred of my clients have died of HIV-related complications. Some of them died horrific deaths, and that is what led me to explore end-of-life issues in an attempt to reduce the likelihood that people would die in such a terrible fashion in the future. One of the first topics I examined was the role of advance directives. I had read that

2. See James L. Werth, Jr., Judith R. Gordon & Ronald R. Johnson, Jr., *Psychosocial Issues Near the End of Life*, 6 *AGING & MENTAL HEALTH* 402, 404-05 (2002). See also *END-OF-LIFE DECISIONS: A PSYCHOSOCIAL PERSPECTIVE* (Maurice D. Steinberg & Stuart J. Youngner eds., 1998); *PSYCHOSOCIAL ISSUES NEAR THE END OF LIFE: A RESOURCE FOR PROFESSIONAL CARE PROVIDERS 3* (James L. Werth, Jr. & Dean Blevins eds., 2006).

3. See *APA WORKING GROUP ON ASSISTED SUICIDE AND END-OF-LIFE DECISIONS, REPORT TO THE BOARD OF DIRECTORS OF THE AMERICAN PSYCHOLOGICAL ASSOCIATION (APA)* 7 (2000), available at <http://www.apa.org/pi/aseol.pdf>.

4. See *id.*

5. James L. Werth, Jr., *Introduction: Behavioral Science and the End of Life*, 46 *AM. BEHAV. SCIENTIST* 195, 195 (2002).

6. Stephen R. Connor, Kathleen A. Egan, Donna M. Kwilosz, Dale G. Larson & Dona J. Reese, *Interdisciplinary Approaches to Assisting with End-of-Life Care and Decision Making*, 46 *AM. BEHAV. SCIENTIST* 340, 340-41, 343 (2002).

over 70% of deaths are negotiated in some way,⁷ which highlighted the importance of advance directives to me.

Despite general support for advance directives, there are real problems with them.⁸ Only about 25% of people have advance directives, and research indicates that those that do exist do “not substantially enhance physician-patient communication or decisionmaking about resuscitation.”⁹ This may be because only 12% of those with an advance directive actually spoke with a physician when drafting it, and more than half never discussed it with their physician at all.¹⁰ Of those who have advance directives, some research indicates that less than half are followed, perhaps because only 5-10% actually provide useful directions about a person’s wishes.¹¹ Of special interest to the Symposium, it has been asserted that even if Terri Schiavo had a living will, it probably would not have made a difference.¹² First, it is very unlikely that it would have been specific enough to apply to her situation, and, second, even if it was, there still would have been a difference of opinion about her medical condition.¹³ A durable power of attorney for health care may be a superior alternative to living wills because these documents appoint someone to speak on another’s behalf. But, in Schiavo’s case, the equivalent of the power of attorney was the court-appointed guardian status accorded to her husband. If Michael Schiavo had been named as his wife’s power of attorney, there still would have been objections because of perceived conflicts of interest.¹⁴ In addition, proxies do not necessarily know what the person wants even if they have had a discussion,¹⁵ so designating a power of attorney is just a small part of the process.

Yet, for all their legal and medical limitations, there can be significant benefits for loved ones if a person has put his or her wishes in writing in a living will. Research has indicated that the post-death stress

7. *In re Guardianship of L.W.*, 482 N.W.2d 60, 85 n.16 (Wis. 1992) (citation omitted).

8. Peter H. Ditto, *Self-Determination, Substituted Judgment, and the Psychology of Advance Decision Making*, in *PSYCHOSOCIAL ISSUES NEAR THE END OF LIFE: A RESOURCE FOR PROFESSIONAL CARE PROVIDERS*, *supra* note 2, at 88-109.

9. Joan Teno et al., *Advance Directives for Seriously Ill Hospitalized Patients: Effectiveness with the Patient Self-Determination Act and the SUPPORT Intervention*, 45 J. AM. GERIATRICS SOC’Y 500, 500 (1997).

10. *Id.*

11. Joan Teno et al., *Do Advance Directives Provide Instructions That Direct Care?*, 45 J. AM. GERIATRICS SOC’Y 508, 510 (1997).

12. Peter H. Ditto, *What Would Terri Want? On the Psychological Challenges of Surrogate Decision Making*, 30 DEATH STUD. 135, 141 (2006).

13. *Id.*

14. See Kathy L. Cerminara, *Theresa Marie Schiavo’s Long Road to Peace*, 30 DEATH STUD. 101, 103 (2006).

15. See Ditto, *supra* note 8.

levels and grieving process are much better for those involved in making decisions to withhold or withdraw treatment if the person who died had expressed his or her values and requests in writing.¹⁶ With the foregoing foundation, I want to illustrate some points about the use of advance directives by discussing three people.

A. "Bill"

The first person I want to talk about is someone to whom I refer as "Bill" for the purposes of this Article. Bill was my first client with HIV who died. Because he was the first one, I was much more involved with him than with many others. I had gone to his house when he was too sick to see me, I went to the hospital when he was admitted, and I sat with him when his wife needed a break. In addition to this involvement, Bill is etched in my mind for two reasons. The first is the magnitude of his pain. I remember that one day I was sitting in his room, talking with his wife, and he was moaning even though he had been sedated. When the physician came in and Bill's wife mentioned the moaning, the physician said Bill could still feel the pain despite the sedation, but he was unwilling to give Bill any more medication for fear that it would hasten Bill's death. This still happens today, fifteen years later, in part because physicians are concerned that they will be investigated by the Drug Enforcement Agency or their state medical board if a patient dies after receiving significant amounts of pain medication.¹⁷

The second thing I remember is that we were one day too late in trying to get Bill to sign an advance directive. For many people, HIV can cause dementia.¹⁸ By the time we got a lawyer to prepare the documentation, Bill could no longer understand what he was signing. Because there was nothing in writing, the hospital refused to grant Bill's wife's pleas that he be allowed to die. Instead, the hospital continued Bill's treatment for weeks, without providing enough pain medication, until his body finally surrendered. The hospital reasoned that they were safer erring on the side of too much treatment rather than not enough.¹⁹

16. Virginia P. Tilden, Susan W. Tolle, Christine A. Nelson & Jonathan Fields, *Family Decision making to Withdraw Life-Sustaining Treatments from Hospitalized Patients*, 50 NURSING RES. 105 (2001).

17. See James L. Werth, Jr., *Reinterpreting the Controlled Substances Act: Predictions for the Effect on Pain Relief*, 20 BEHAV. SCI. & L. 287, 289 (2002).

18. Mohammad Ghafouri, Shohreh Amini, Kamel Khalili & Bassel E. Sawaya, *HIV-1 Associated Dementia: Symptoms and Causes*, 3 RETROVIROLOGY 28 (2006), available at <http://www.retrovirology.com/content/3/1/28> ("Among the viruses infecting the brain, human immunodeficiency virus type 1 (HIV-1) is the most common cause of dementia . . .").

19. This episode took place not long after the Supreme Court's decision in *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261 (1990), which upheld a Missouri statute requiring clear and convincing evidence as to an incompetent person's wishes before permitting a surrogate to

In addition, as is often the case in such situations, CPR was performed on Bill, resulting in broken ribs and more pain.²⁰ I still remember the look on his wife's face during and after these horrific final weeks.

B. Josh

The next person is a man I never personally met, except through his sister, Laura. Laura tells her story in a special issue of the journal *Death Studies*, which dealt largely with the *Schiavo* case.²¹ As Laura reports in her article, Josh Crow was stopped at a red light while riding his motorcycle when a truck moving at an estimated fifty miles per hour ran into the motorcycle.²² The crash sent Josh flying through the air; his helmet came off, and he hit the ground hard, causing significant head trauma and many bone fractures.²³ Josh came out of a coma but only to exist in a persistent vegetative state.²⁴ Laura's interpretations of Josh's movements gave her hope that he would recover²⁵ in a way eerily similar to that of the relatives of Terri Schiavo.

Because her father was emotionally incapacitated by the events, Laura became the surrogate decisionmaker. Josh was less than thirty years old. He didn't have any advance directives, but Laura and her dad believed they knew what Josh would have wanted. They were eventually able to get him into a hospice where his pain was immediately treated. Josh and the family were provided care, and they were given the option of removing the feeding tube consistent with the guidelines from various organizations, as well as state law.²⁶ Josh died exactly three years before Terri Schiavo, but his dying process and his family's decisionmaking process were much different and probably more typical, even though there was no advance directive.

withdraw life-sustaining treatment. This evidentiary standard was designed to "assure that the action of the surrogate conform[ed] as best it [could] to the wishes expressed by the patient while competent." *Id.* at 280. The law of end-of-life decisionmaking was therefore unclear at this time, but *Cruzan* likely contributed to the hospital's decision to err on the side of life.

20. See generally Betty A. Ditillo, *Should There Be a Choice for Cardiopulmonary Resuscitation When Death is Expected? Revisiting an Old Idea Whose Time Is Yet to Come*, 5 J. PALLIATIVE MED. 107 (2002).

21. Laura Crow, *Extreme Measures: A Personal Story of Letting Go*, 30 DEATH STUD. 177 (2006).

22. *Id.*

23. *Id.*

24. *Id.* at 178.

25. *Id.* at 183.

26. See Kathy L. Cerminara, *Three Female Faces: The Law of End-of-Life Decision-Making in America*, in DECISION-MAKING NEAR THE END OF LIFE: RECENT DEVELOPMENTS AND FUTURE DIRECTIONS (J. L. Werth, Jr. & D. Blevins eds., forthcoming 2007); Joshua E. Perry, Larry R. Churchill & Howard S. Kirshner, *The Terri Schiavo Case: Legal, Ethical, and Medical Perspectives*, 143 ANNALS INTERNAL MED. 744, 745 (2005).

C. *Becky*

The third person whose death I want to describe is closer to me, and because I was more intimately involved in the process, I have more to say. My fiancée, Becky, died one month after her thirtieth birthday, when her lungs failed as a result of complications associated with Hodgkin's Disease.²⁷ Even though she was young like Josh, Becky knew she had an illness that might be terminal. She liked to be in control, so she drew up a living will and named her sister, who was a long-term care nurse, as her power of attorney. Becky was very clear with her whole family that she did not want to be placed on a ventilator and did not want other artificial means employed to maintain her life. Because we started our relationship well into the course of her disease, I was not around when she made her advance directives. Nevertheless, I supported her decisions. My biggest regret is that we never officially changed her power of attorney form so that I could share the responsibility with her sister.

The day after she bought her wedding dress, I took Becky into the hospital for what would be the last time. She had been having trouble breathing, but because she had been accepted into a clinical trial for her illness, we were hoping she would just need some treatment to keep her lungs open long enough for the trial to begin, a little over a week later. Becky's condition progressively worsened, and her physician wanted to put her on a ventilator. According to her living will, this was not acceptable. She agreed, however, with her sister and the physicians that she would go on the machine for one week. The physicians assured her that the goal was to get her breathing on her own so she could travel to Maryland to start the trial. After several surgeries, she was able to get off the ventilator but still had to be on oxygen. Unfortunately, when the medical staff tried to give her a breathing treatment, her lungs could not take it and her vital signs dropped. They then wanted to put her back on the ventilator but acknowledged there was nothing else they could do to improve the condition of her lungs. Consistent with her verbal instructions and the instructions of her sister as power of attorney, her father and I refused to allow them to put her back on the ventilator. Becky died about fifteen hours later on the same day she was supposed to start the clinical trial that may have saved her life. She wanted to die at home, but given her health status, we could not get her out of the hospital. Even if we were able to, it probably would not have been in her best interest because we would not have had access to the pain management she needed.

27. See generally James L. Werth, Jr., *Becky's Legacy: Personal and Professional Reflections on Loss and Hope*, 29 DEATH STUD. 687 (2005).

Although Becky and Terri Schiavo were similar in age and gender, the reader probably has never seen or heard of Becky until now. She was not discussed in the newspapers, magazines, nightly news, courts, or legislatures. But in some respects, she represents the tens of thousands of people who die each year in this country when medical treatment is withheld or withdrawn (which probably happens in the majority of all deaths in the hospital).²⁸ On the other hand, Becky was among the minority who actually put her end-of-life wishes in writing. Although there is overwhelming support for advance directives (though there are significant differences across cultural groups, as will be discussed later in this Article), only about 25% of Americans actually have one.²⁹

IV. FAMILY ISSUES

Moving from the individual to the family, one of the most memorable aspects of the situation involving Terri Schiavo was the bitter feuding between her husband and her parents and siblings. Based on this acrimony, one might think that family conflict is commonplace in end-of-life situations. Research indicates, however, that conflict is much more likely between the family and the medical team than among family members.³⁰ For example, it has been reported that 8-24% of families have internal conflict, but 40-48% have conflicts with the medical team.³¹ However, there are some situations where internal disputes are more likely to arise, including when the dying person's partner is unwelcome for any number of reasons by the dying person's family. This conflict can make the process harder for the dying person and for the partner and family before the death and during the grieving process. In this section, I contrast the dying process of two people I knew.

A. Sam

Sam is a gay man who first was a client of mine a few years ago, initially because of some court-ordered treatment. During our work together, his prior partner died. This gave us occasion to talk about grief, and I shared with him my experience with Becky so he knew I had a sense of what his grief was like. We finished the sessions required by the court, in addition to a couple more to help him through the worst of his grief. Not long before I wrote this Article, he called me again

28. See Kathy Faber-Langendoen & Paul N. Lanken, *Dying Patients in the Intensive Care Unit: Foregoing Treatment, Maintaining Care*, 133 ANNALS INTERNAL MED. 886, 888 (2000).

29. See Ditto, *supra* note 12, at 141-42.

30. See Lori A. Roscoe, Hana Osman & William E. Haley, *Implications of the Schiavo Case for Understanding Family Caregiving Issues at the End of Life*, 30 DEATH STUD. 149, 154 (2006).

31. *Id.*

because the partner he had been with during our prior work had just died. Although he certainly knew what to expect with grief, he did not know how to handle grief while being shut out by his partner's family.

Because they were a gay couple, Sam had no rights, even though he and his partner had been together for several years, shared a house, and pooled finances, and notwithstanding the fact that Sam served as his partner's caregiver after his partner became ill.³² Under most state laws, the first choice of guardian is typically the spouse, but for Sam and his partner, as well as for same-sex couples in much of the country, marriage is not an option. Because Sam's partner's family never accepted their relationship or Sam, as soon as his partner died, the family got a court order that prevented Sam from approaching the house, changed the locks, and would not let him have any personal belongings. The family also wanted an autopsy because they thought Sam might have contributed to their son's/brother's death. Needless to say, this was very difficult for Sam. Over and above his partner's sudden death, Sam was accused of murder, lost his home and all of his personal and shared effects, including pictures and mementos, and had no legal recourse. Research has shown that the people who are most likely to need legal protection – men and women in same-sex partnerships who have not disclosed their relationship to their family – are less likely to have engaged in advance care planning, which is obviously problematic from both psychological and legal perspectives.³³

B. *Becky*

The case was very different for Becky's family in general and with me, in particular. Her father could have fought to have Becky put back on the ventilator, but he knew that was not what she wanted. He also could have held a grudge against Becky's sister for making the decision to follow the verbal agreement to stop treatment. Yet, he has seen how hard it was and has continued to be for Becky's sister to know that ultimately she was the one who decided that, consistent with the advance directive, Becky should not be reconnected to the ventilator. The family has rallied around Becky's sister, visits the grave together, participates in American Cancer Society fundraising and awareness events as a team, and talks in loving terms about Becky. They have continued to welcome me into their home, and Becky's father refers to me as his son-in-law,

32. See Ellen D. B. Riggle & Sharon Scales Rostosky, *For Better or For Worse: Psycholegal Soft Spots and Advance Planning for Same-Sex Couples*, 36 PROF. PSYCHOL.: RES. & PRAC. 90, 90-91 (2005).

33. See Ellen D. B. Riggle, Sharon S. Rostosky & Robert A. Prather, *Advance Planning by Same-Sex Couples*, 27 J. FAM. ISSUES 758, 762 (2006).

and her sister refers to me as her brother. I know it is hard for them to see me because I remind them of her and of her death, but they believe that it is best for everyone to stay together and share the grief.

V. RELIGIOUS/SPIRITUAL BELIEFS

Becky and her family have a strong faith as well. They may have questioned why she became ill, but they never blamed their God for her condition and her death. In this way, their religious beliefs were a source of comfort for them, both while she was ill and after she died. Becky's end-of-life decisions were not inconsistent with her family's perception of what their religion allowed. For others, however, faith and religious or spiritual beliefs may create some difficulties when, for example, there are disagreements about what are acceptable or preferable actions. These disagreements may be based on misunderstandings of what the person's faith system actually allows or encourages at the end of life. For example, when the Pope said that food and fluids should always be provided, this conflicted with the Catholic Church's formal position on artificial nutrition and hydration.³⁴ This may have confused people. Difficulties may also arise if an individual's belief system is different from the beliefs of providers or other family members; for example, when a Jehovah's Witness refuses a blood transfusion or when a patient believes that suffering is important. I next use examples to illustrate the ways religion and spirituality can help or hinder the dying and grieving processes.

A. Thomas

As one example of how religion may be helpful for the dying person and loved ones in coping and making decisions, I briefly mention Thomas. I saw Thomas several years ago. He was referred to me because he was in the end stages of AIDS, and his medical treatment had stopped working. The clinic staff who referred him thought he should be on hospice and wanted me to convince him that this would be his best option because his pain and other physical symptoms would likely be better managed and because he would be able to stay at home. I am a strong believer in hospice care, so I shared the clinical team's perspective. However, Thomas and his mother, who was his caregiver, believed that God made decisions about when people die and that it was not up to them to give up on trying different forms of treatment that God had provided.³⁵ So, Thomas died while trying new medications and thera-

34. See Jay Wolfson, *Defined by Her Dying, Not Her Death: The Guardian Ad Litem's View of Schiavo*, 30 DEATH STUD. 113, 118 (2006).

35. See Charlotte B. Johnson & Susan C. Slaninka, *Barriers to Accessing Hospice Services*

pies and accepted his discomfort because he thought that is what God wanted him to do. His mother was also able to draw on her faith and her church community both during Thomas' dying process and after he died. She indicated that she had no regrets about their decision because it was consistent with their faith.

B. *Josh*

Although a vast majority of people in the United States say they have faith, there are a variety of reasons why people may not want to join a church or formal religion. Josh, whom I discussed above, and his family were like this. Josh and Laura, his sister, had negative views of organized religions. Laura said that after Josh's accident she would become upset if people recommended that she pray or indicated they would pray for Josh or when people would say it was "God's will" that this happened or referred to a "greater plan." Laura told me that she felt as if other people were trying to force their religious perspectives on her and were judging Josh and her based on their own beliefs. Instead of being comforted, Laura was frustrated and angered by this behavior. She said that she did find comfort in her own spiritual belief system, but it was the imposition by others that was the problem.

VI. MULTICULTURAL INFLUENCES

Religious or spiritual beliefs may be considered one type of cultural diversity.³⁶ This can mean that those like Josh and Laura, who do not adhere to predominant Christian values, may have their beliefs discounted. This happens a great deal in our society. For example, the legal and medical systems in the United States are based on a European American male point of view, where individuality and autonomy are prized and primary considerations.³⁷ This can be seen in the ways in which informed consent requirements are interpreted and applied.³⁸ However, for some cultures, collectivism and joint decisionmaking, or deferring to others, is preferred and expected.³⁹ It is important to note that although there is a strong preference for individual autonomy in the medical system in the United States, a person can also exert autonomy

Before a Late Terminal Stage, 23 DEATH STUD. 225, 235 (1999) (explaining that caregivers' perception of hospice as a "last ditch service" may be one reason why enrollment rate is so low and occurs late in the process).

36. See James L. Werth, Jr. et al., *The Influence of Cultural Diversity on End-of-Life Care and Decisions*, 46 AM. BEHAV. SCIENTIST 204, 204 (2002).

37. *Id.* at 206.

38. *Id.*

39. *Id.* at 206-07.

by giving up control to others.⁴⁰ Thus, an elderly Asian woman legally can decide to have her eldest son receive the medical information and let him make decisions for her.⁴¹

Therefore, what many European Americans, especially those working within the legal and medical systems, believe is normal and proper may actually be at odds with some ethnic groups' values. For example, although the potential virtues of advance directives are extolled in legal and medical journal articles,⁴² some Native Americans believe that to talk about something is to cause it to happen.⁴³ In other words, according to these Native Americans, talking about death and what to do if someone becomes incapacitated may actually cause death to occur.⁴⁴ This obviously creates problems for them when others try to fit them into the majority perspective of advance care planning and living wills. There are also numerous other examples of different perspectives on end-of-life decisions based on age, ethnicity, or gender.⁴⁵ On the other hand, it is important that we do not assume that merely because a person appears to belong to a given group that he or she will automatically hold certain beliefs. We also need to be aware that our own views may be culturally encapsulated. Two cases illustrate these points.

A. Darryl

Darryl was another one of my early clients. He was an African-American man who had lived in California and returned to rural Alabama to receive care from his mother and to die at home. Because they lived outside the town of Tuskegee for decades, a lack of trust in the medical system was a part of their heritage and experience.⁴⁶ In fact, none of my African-American clients would participate in clinical trials and were reluctant to visit public health facilities. Throughout his illness, Darryl and his mother had difficulty receiving medical care from predominantly white providers.

As Darryl's health deteriorated, he and his mother also refused to

40. *See id.* at 206.

41. *Id.* at 206-07.

42. *See* Linda L. Emanuel, Michael J. Barry, John D. Stoeckle, Lucy M. Ettelson & Ezekiel J. Emanuel, *Advance Directives for Medical Care – A Case for Greater Use*, 324 *NEW ENG. J. MED.* 889 (1991); *see also* Amy R. Lipson, Alice J. Hausman, Patricia A. Higgins & Christopher J. Burant, *Knowledge, Attitudes, and Predictors of Advance Directive Discussions of Registered Nurses*, 26 *W. J. NURSING RES.* 784 (2004).

43. *See* Joseph A. Carrese & Lorna A. Rhodes, *Western Bioethics on the Navajo Reservation: Benefit or Harm?*, 274 *J. AM. MED. ASS'N* 826, 826-27 (1995).

44. *See id.*

45. *See* Werth et al., *supra* note 36, at 211-13.

46. *See generally* JAMES H. JONES, *BAD BLOOD: THE TUSKEGEE SYPHILIS EXPERIMENT* (2d ed. 1993).

consider any sort of advance directive because they thought that living wills could only be used to limit care. Further, as many African Americans, especially those who are poor, have said to me: "Why would I do anything to limit care; I just now am able to get into your hospitals, so why would I give you an excuse to kill me sooner than the staff would otherwise?" This is consistent with the research on attitudes of ethnic minority group members, which shows that they generally tend to be much more skeptical of advance directives and much less likely to have them.⁴⁷ These attitudes also relate to studies done on pain management that show differences in the amount of pain medication provided to ethnic minority group members and how long they have to wait to receive it.⁴⁸

B. *Juan*

Juan's story effectively demonstrates that just because a person is a member of a visible ethnic minority group does not necessarily mean that he or she will believe the same things as other group members. Juan was an undocumented immigrant from South America. He was referred to me because he was depressed. In my practice, because of ethical and legal obligations, I start the first counseling session with a statement about informed consent. My standard introduction includes a series of statements about confidentiality, during which I tell my clients (among other things) that our conversations will remain private unless I become concerned that the client may hurt himself or herself or someone else. That part of the informed consent discussion is as far as I got before Juan interrupted me and said that he believed it was his right to kill himself, and if I could not handle that, then I needed to refer him elsewhere. It actually is not unusual for my clients to talk about suicide, and my examinations of case law, statutes, mental health profession ethics codes, and literature on the standard of care in this area have led me to conclude that my discussions with clients regarding their suicidal ideations do not present an ethical or clinical problem, as long as I act prudently.⁴⁹ However, this was the first time one of my clients who was an immigrant from South or Central America indicated that he or she

47. See Werth et al., *supra* note 36, at 212.

48. See Carmen R. Green et al., *The Unequal Burden of Pain: Confronting Racial and Ethnic Disparities in Pain*, 4 PAIN MED. 277 (2003).

49. See James L. Werth, Jr., *Legal and Ethical Considerations for Mental Health Professionals Related to End-of-Life Care and Decision-Making*, 46 AM. BEHAV. SCIENTIST 373 (2002); James L. Werth, Jr., *Mental Health Professionals and Assisted Death: Perceived Ethical Obligations and Proposed Guidelines for Practice*, 9 ETHICS & BEHAV. 159 (1999); James L. Werth, Jr., *Rational Suicide and AIDS: Considerations for the Psychotherapist*, 20 COUNSELING PSYCHOLOGIST 645, 652-54 (1992).

was considering suicide, and I was surprised because this is not a cultural norm for people from those regions of the world. Juan and I were able to work through this and do good work together. As far as I know, he is still alive.

VII. CONTINUING AND EMERGING CONTROVERSIAL DECISIONS

In conclusion, I want to briefly mention a few emerging, controversial areas with prominent psychosocial dimensions that are related to end-of-life decisions. First, one cannot talk about controversy and end of life without at least mentioning assisted suicide and the state of Oregon. A recent Supreme Court case, *Gonzales v. Oregon*,⁵⁰ has most likely been mentioned elsewhere in this issue. One important thing to note, however, is that even though assisted suicide is officially legal in only Oregon, it is practiced in unregulated fashion across the country.⁵¹ In addition, commentators, including myself, believe that it is artificial to differentiate among various end-of-life decisions based on the underlying rationales for intervention.⁵² For example, when discussing assisted suicide, concern is often expressed that the person may want to die because of clinical depression; however, it is also possible that a person may want to discontinue treatment, such as dialysis, because of depression.⁵³ To be consistent, if one believes intervention is necessary in cases of assisted suicide, one should also believe it is necessary in other end-of-life situations. This issue may receive more attention in the future.

50. 126 S. Ct. 904 (2006) (holding that the Controlled Substances Act does not authorize the U.S. Attorney General to bar physicians from prescribing controlled substances for use in assisted suicide in the face of a state statute permitting such conduct).

51. Diane E. Meier, Carol-Ann Emmons, Ann Litke, Sylvan Wallenstein & R. Sean Morrison, *Characteristics of Patients Requesting and Receiving Physician-Assisted Death*, 163 ARCHIVES INTERNAL MED. 1537, 1537 (2003) ("Amid continued controversy, national surveys suggest that 1 in 5 physicians in the United States have received at least 1 request to assist a terminally ill patient to die, and approximately 3% to 18% accede to these requests despite legal prohibition against the practice in all states but Oregon."); see also Ezekiel J. Emanuel, Elisabeth R. Daniels, Diane L. Fairclough & Brian R. Clarridge, *The Practice of Euthanasia and Physician-Assisted Suicide in the United States: Adherence to Proposed Safeguards and Effects on Physicians*, 280 J. AM. MED. ASS'N 507, 508-09 (1998).

52. See Timothy E. Quill, Barbara Coombs Lee & Sally Nunn, *Palliative Treatments of Last Resort: Choosing the Least Harmful Alternative*, 132 ANNALS INTERNAL MED. 488, 492 (2000); Timothy E. Quill, Bernard Lo & Dan W. Brock, *Palliative Options of Last Resort: A Comparison of Voluntarily Stopping Eating and Drinking, Terminal Sedation, Physician-Assisted Suicide, and Voluntary Active Euthanasia*, 278 J. AM. MED. ASS'N 2099, 2099 (1997); James L. Werth, Jr., *How Do the Mental Health Issues Differ in the Withholding/Withdrawing of Treatment Versus Assisted Death?*, 41 OMEGA 259, 263 (2000).

53. Werth, *supra* note 52; see also Laurie Rosenblatt & Susan D. Block, *Depression, Decision Making, and the Cessation of Life-Sustaining Treatment*, 175 W. J. MED. 320 (2001); James L. Werth, Jr., *The Relationships Among Clinical Depression, Suicide, and Other Actions That May Hasten Death*, 22 BEHAV. SCI. & L. 627, 632-39 (2004).

Another controversial area of which readers may not be aware relates to an organization called NuTech, which was formed by right-to-die activists who were frustrated with the lack of success in legislatures and who decided to take matters into their own hands.⁵⁴ The reader may be familiar with Derek Humphry's book *Final Exit*; however, most people do not have access to drugs, and a great many find the idea of dying with a plastic bag over their head unappealing.⁵⁵ Consequently, the NuTech movement is designed to provide people with legal, everyday available means to hasten death in a way that will not look like assisted suicide.⁵⁶ Currently, there are non-medically trained people who will assist those who request assistance in dying.⁵⁷ The eventual goal of NuTech, however, is to develop a means that does not require assistance.⁵⁸

Finally, I want to mention the controversial issue of medical futility.⁵⁹ Basically, this concept encompasses a situation in which a person wishes to receive treatment or have a loved one receive treatment, but the medical team believes that it is not medically appropriate or is "futile" to do so, and care should be stopped.⁶⁰ During the time the publicity in the *Schiavo* case was at its maximum, a medical futility case in Texas flew under the media's radar. Sun Hudson was an infant who, in what may have been the first case of the application of a state futility law,⁶¹ had necessary life-sustaining treatment withheld over the wishes of his mother, resulting in his death.⁶² The Texas statute was supported by the National Right to Life Committee and was signed by President George W. Bush while he was governor of Texas.⁶³ Ironically, this situation occurred while the president, disability rights groups, religious groups, and others were making comments about erring on the side of

54. Russel D. Ogden, *Non-Physician Assisted Suicide: The Technological Imperative of the Deathing Counterculture*, 25 DEATH STUD. 387, 388-90, 397 (2001).

55. See DEREK HUMPHRY, FINAL EXIT: THE PRACTICALITIES OF SELF-DELIVERANCE AND ASSISTED SUICIDE FOR THE DYING 95-99 (1991) (describing ways in which a terminally ill individual can contemplate and potentially plan suicide using everyday materials); Ogden, *supra* note 54, at 388.

56. Ogden, *supra* note 54, at 396-97.

57. *Id.* at 395-96.

58. See *id.* at 396.

59. See James L. Werth, Jr., *Concerns About Decisions Related to Withholding/Withdrawing Life-Sustaining Treatment and Futility for Persons with Disabilities*, 16 J. DISABILITY POL'Y STUD. 31, 33-34 (2005).

60. *Id.* at 33-35.

61. See Advance Directives Act, TEX. HEALTH & SAFETY CODE ANN. § 166.046(e) (1999).

62. *Houston Mother Loses Fight to Keep Baby on Life Support*, NBC5.COM, Mar. 15, 2005, <http://www.nbc5.com/health/4286333/detail.html??z=dp&dpswid=1167317&dppid=65194>.

63. Answers.com, Sun Hudson Case, <http://www.answers.com/topic/sunhudson> (last visited Oct. 29, 2006).

life to argue that Terri Schiavo should be kept alive.⁶⁴

Psychosocial issues such as mental health conditions, family involvement, and cultural considerations are important aspects of end-of-life issues and decisions, including the abovementioned emerging, controversial issues. Although I certainly do not intend to downplay the importance of the medical and legal components of end-of-life situations, I believe it is imperative to emphasize the need to keep psychosocial aspects part of the discussion in order to maintain the humanity of the dying and grieving participants.

64. *See id.*