3rd International Society of Advance Care Planning and End of Life care Conference

A review of evidence supporting certain disability rights concerns about "end of life" advocacy

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CASE STUDY: Bill's Story

Bill, a paraplegic anthropology professor, was hospitalized for a stage 4 pressure sore. One night, a "hospitalist" visited him:

"He grimly told me I would be bedbound for at least six months and most likely a year or more. That there was a good chance the wound would never heal. If this happened, I would never sit in my wheelchair. I would never be able to work again."

Excerpt from Bad Cripple blog by Bill Peace, soon to appear in the Hastings Center Report. http://badcripple.blogspot.com/2012_04_01_archive.html

CASE STUDY: Bill’s Story

“Not close to done, he told me I was looking at a life of complete and utter dependence. My medical expenses would be staggering. Bankruptcy was not just possible but likely. Insurance would stop covering wound care well before I was healed. Most people with the type of wound I had ended up in a nursing home.”

CASE STUDY: Bill's Story

"His next words were unforgettable. The choice to receive antibiotics was my decision and mine alone. He informed me I had the right to forego any medication, including the lifesaving antibiotics. If I chose not to continue with the current therapy, I could be made very comfortable. I would feel no pain or discomfort at all. Although not explicitly stated, the message was loud and clear. I can help you die peacefully."

CASE STUDY: Bill’s Story

“I never told anyone about what transpired. Not my family, friends, the nurses I saw for over a year when I was bedbound. I did not tell anyone for a very good reason: I was scared. Terrified really. A physician, a person who is highly educated, and I would hope free of any bias considered my life not worth living. Disability was a fate worse than death. It was the ultimate insult.”

Does end-of-life group shut out disability perspective?

"It was a deliberate decision -- and it was irresponsible."

Dr. Ira Byock, author of Dying Well and one of the founders of Partnership for Caring, is adamant about what he sees as that "end-of-life" organization's failure to seek the input of disability rights groups.

M Johnson, A deliberate decision?

Ragged Edge Magazine July 21, 2003 http://www.raggededgemagazine.com/extra/pfc-ndy07103.html

The first step to addressing the weaknesses of advance care planning is admitting that weaknesses exist.

A Disability Perspective:
The Quest for Balance

Quality of Life Judgments

Physicians devalue the quality of life of people with disabilities compared to our own assessments.

Gerhart, K. A., Kozoil-McLain, J., Lowenstein, S.R., & Whiteneck, G.G. (1994). Quality of life following spinal cord injury: knowledge and attitudes of emergency care providers. Annals of Emergency Medicine, 23, 807-812;

Cushman, L.A & Dijkers, M.P. (1990). Depressed mood in spinal cord injured patients: staff perceptions and patient realities, Archives of Physical Medicine and Rehabilitation, 1990, vol. 71, 191-196).

Organ Transplant Eligibility – What Are Amelia's Options?

Brick Walls: "I am going to try and tell you what happened to us on January 10, 2012, in the conference room in the Nephrology department at Children's Hospital of Philadelphia. . . . We are in the year 2012 and my child still does not have the right to live, the right to a transplant, because she is developmentally delayed." http://wolfhirschhorn.org/brick-walls/

Following a national petition drive and negative publicity, the hospital's position changed.

In a statement released jointly with Joe and Chrissy Rivera today, a hospital official also promised to review the way the hospital handles such cases. . . . "As an organization, we regret that we communicated in a manner that did not clearly reflect our policies or intent and apologize for the Riveras' experience," said Michael Apkon, senior vice president and chief medical officer. He added: "While we can unequivocally state that we do not disqualify transplant patients on the basis of intellectual ability... this event underscores the importance of our responsibility to effectively communicate with families.“ USA Today, 2-15-12

Organ procurement from newly injured people – UNOS proposal

Deleted: Before evaluating a patient as a DCD candidate, the hospital's primary healthcare team and the legal next of kin must have decided to withdraw ventilated support or other life-sustaining treatment and that decision must be documented in the patient's chart.

New: A potential DCD donor should [delete: then] be evaluated by the primary healthcare team and the local OPO to determine if the candidate meets the following criteria . . .

Organ procurement from newly injured people – UNOS proposal

"1. A patient with a permanent and irreversible neurological injury (i.e. upper spinal cord injury), or permanent and irreversible disease (i.e. end-stage musculoskeletal or pulmonary disease) that results in necessary life-sustaining medical treatment or ventilated support may be a suitable candidate for DCD. . . ."

UNOS Proposal to Update and Clarify Language in the DCD [Donation After Circulatory Death] Model Elements, March 2011

Not Dead Yet comment on UNOS proposal:

“[T]he new protocol raises the concern that the potential for organ donation could become a factor that weighs in favor of a decision to withdraw life-sustaining treatment. This concern is relevant whether the decision maker is the disabled individual, who may be going through difficult changes in his or her health or other circumstances, or a surrogate decision-maker, who may be a caregiver or have other complex personal and conflicted interests in the decision.”

[NDY Comment letter 1/3/2012.]

Changing our minds . . .

"… [R]esearch indicates that patients often changed their minds when confronted with the actual situation or as their health status changed. Some patients who stated that they would rather die than endure a certain condition did not choose death once that condition occurred."

HHS: Advance Care Planning Preferences for Care at the End of Life, citing Lynn J, Arkes HR, Stevens M, et al. Rethinking fundamental assumptions: SUPPORT's implications for future reform. J Am Geriatr Soc 2000;48(5):S214-21.

Terminal Uncertainty

17 percent of patients [outlived their prognosis] N.A. Christakis and T.J. Iwashyna, "Attitude and Self-Reported Practice Regarding Prognostication in a National Sample of Internists," Archives of Internal Medicine, Vol. 158, Num. 21 November 23, 1998, pp. 2389-95;

This roughly coincides with data collected by the National Hospice and Palliative Care Organization, which in 2007 showed that 13 percent of hospice patients around the country outlived their six-month prognoses. ...

Terminal Uncertainty

“When a group of researchers looked specifically at patients with three chronic conditions—pulmonary disease, heart failure, and severe liver disease—they found that many more people outlived their prognosis than in the Christakis study. Fully 70 percent of the 900 patients eligible for hospice care lived longer than six months, according to a 1999 paper published in the Journal of the American Medical Association." See Nina Shapiro, "Terminal Uncertainty," Seattle Weekly, January 14, 2009, available at http://www.seattleweekly.com/content/printVersion/553991

The Top 2 Statutory Surrogates Are the Top 2 Elder Abuse Perpetrators

In a telephone survey of nearly 6,000 elderly individuals, victims of elder physical mistreatment reported that:

- A majority (57 percent) of perpetrators of physical abuse were partners or spouses.

Acierno R., M. Hernandez-Tejada, W. Muzzy, K. Steve. National Elder Mistreatment Study (pdf, 183 pages), NCJ 226456, March 2008, Grant Report.

The Top 2 Statutory Surrogates Are the Top 2 Elder Abuse Perpetrators

"Adult children are the most frequent abusers of the elderly, ... Other family members and spouses ranked as the next most likely abusers of the elderly."

Toshio Tatara, PhD. and Lisa M. Kuzmeskus, M.A. for the National Center on Elder Abuse Grant No. 90-am-0660 (Washington, DC: May 1996)

Advance directives are mistakenly thought to always refuse treatment.

A recent study in the Journal of Emergency Medicine:

- Researchers from the University of Pittsburgh Medical Center
- Survey responses from more than 700 physicians in 34 states

1) Found that over 50% of physicians misinterpreted a living will as having a "do not resuscitate" (DNR) order when it did not.

2) About the same percentage over-interpreted DNR orders as meaning no treatment except "comfort care" or "end-of-life" care.

Mirarchi, et al., TRIAD III: Nationwide Assessment of Living Wills and No Not Resuscitate Orders, Journal of Emergency Medicine, Volume 42, Issue 5 , Pages 511-520, May 2012

Futility Policies Recommended by AMA

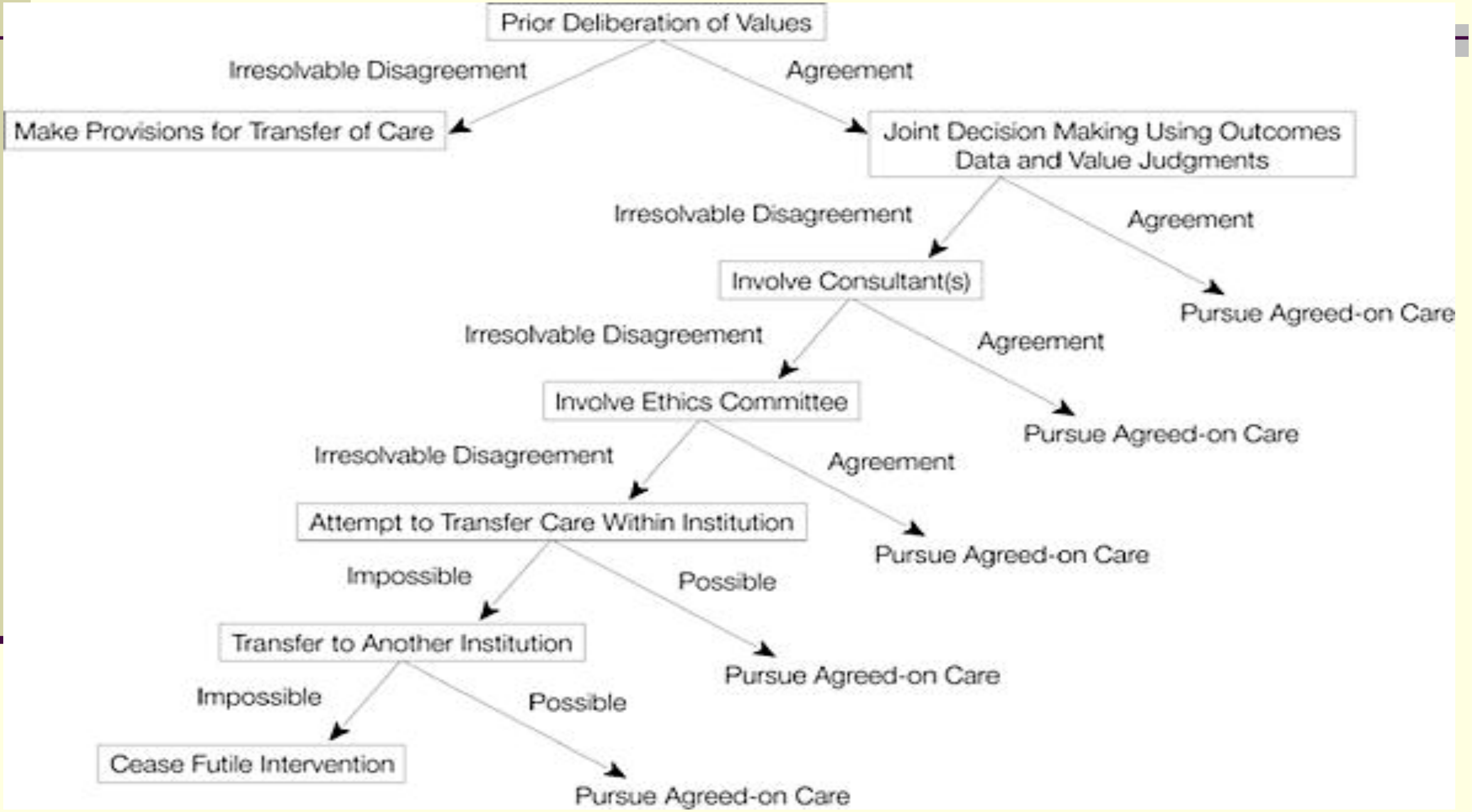
The Journal of the American Medical Association, Volume 281(10).March 10, 1999.937-941

Medical Futility in End-of-Life Care: Report of the Council on Ethical and Judicial Affairs

JAMA:

“When medical cases involve futility judgments, case-by-case evaluations using a fair process approach may well be the best available option; it acknowledges both the impossibility of attaining objective assurance [that treatment is futile] and the necessity of proceeding fairly.”

JAMA


Prior Deliberation of Values
Irresolvable Disagreement
Agreement
Make Provisions for Transfer of Care
Joint Decision Making Using Outcomes Data and Value Judgments
Irresolvable Disagreement
Agreement
Involve Consultant(s)
Pursue Agreed-on Care
Irresolvable Disagreement
Agreement
Involve Ethics Committee
Pursue Agreed-on Care
Irresolvable Disagreement
Agreement
Attempt to Transfer Care Within Institution
Pursue Agreed-on Care
Impossible
Possible
Transfer to Another Institution
Pursue Agreed-on Care
Impossible
Possible
Cease Futile Intervention
Pursue Agreed-on Care

Futility by Due Process/Stacked Deck

“When there is a request for treatment that the physician feels is inappropriate, an ethics consultation may be requested. If the guidelines of the statute are followed, the law creates a legal safe harbor for both physicians and hospitals by granting immunity from civil and criminal liability.”

Fine & Mayo, Resolution of Futility by Due Process: Early Experience with the Texas Advance Directives Act, Ann Intern Med 2003; 138: 743-746.

Rush to Judgment

"Once a patient progresses to minimal consciousness, we can't predict what's going to happen," says Dr. Joseph J. Fins, chief of medical ethics at Weill Cornell Medical College and author of a coming book, "Rights Come to Mind: Brain Injury, Ethics and the Struggle for Consciousness.". . . .

- A Drug That Wakes the Near Dead, NYTimes Magazine, Jeneen Interlandi, Dec 1, 2011

Rush to Judgment

It is not uncommon for doctors to assume the worst and advise family members to withdraw care early. They do so in part because they see their duty as helping loved ones face reality. But Fins argues that this is a cop-out. "It's glossing over all the unknowns for the sake of a quicker, cleaner solution," he says. "It's wrong to be so uniformly fatalistic so early on, especially with all the data emerging about the prospects for later-stage recovery."

A Drug That Wakes the Near Dead, NYTimes Magazine, Jeneen Interlandi, Dec 1, 2011

5/24/12: National Disability Rights Network issues groundbreaking report

In fact, there are times, as this report will describe where physicians recommend and family or other surrogate decision makers decide to not provide a needed transplant, to withhold medical treatment including hydration and nutrition of individuals

without a terminal condition . . .. Applied in these ways, medical decision making and procedures are discriminatory and deny basic constitutional rights to individuals with disabilities including the rights to liberty, privacy, and other statutory and common law rights. [Page 11.]

Devaluing People with Disabilities: Medical Procedures that Violate Civil Rights, at www.ndrn.org

5/24/12: National Disability Rights Network issues groundbreaking report

Hospitals, medical establishments and other medical entities' reliance on ethics committees and consultations are insufficient protections of patient's legal rights and they must, therefore, establish and implement due process protections to ensure the civil rights of a person with a disability are protected when … there is a perceived or actual conflict between the desires of parents or guardians and the civil and human rights of a person with a disability. These due process procedures must … be in place for instances of withholding necessary medical treatment including but not limited to nutrition, hydration or antibiotics. [Page 53.]

Nothing About Us Without Us

A constructive relationship between the disability and palliative care communities could be developed based on recognition that healthcare policies affecting people with disabilities must be formulated with people with disabilities “at the table.”