
Shared Decision Making: The Ethics of Caring and Best Respect

by Joseph E. Beltran

Making decisions regarding life-sustaining treatments for patients who are severely disabled involves some of the most difficult clinical dilemmas in bioethics. This paper focuses on two aspects of this kind of decision making: accurately determining a mentally disabled patient's decision-making capacity; and making treatment decisions for patients who have never had or who do not currently have decision-making capacity and who have no available surrogate. The author examines legislative and community-based solutions and discusses future issues facing developmentally disabled persons, including the need for a legally recognized advance directive and the ramifications of physician-assisted death for this population.

Decisions concerning life-sustaining treatments are difficult and complicated enough when the choices involve a competent patient with family and health care team support. These choices become even more complicated when they involve disabled patients whose decision-making capacity runs along a dynamic continuum.

This paper will address two ethical dilemmas that frequently occur when considering treatment decisions for persons with mental retardation and developmental disabilities: 1) making an accurate assessment of decision-making capacity, and 2) deciding for patients who lack decision-making capacity and have no available surrogate. The paper will examine recent legislative and community-based solutions to these dilemmas as well as potential future issues.

Case Examples

Case examples are useful in illustrating the difficulty, diversity, and conflict that can emerge when considering decision making for patients with developmental disabilities, including persons with mental retardation.

Case Example — Sandra Jensen

Sandra Jensen is a thirty-five-year-old

woman who has worked most of her adult life on behalf of the mentally disabled population. In California the definition of a developmentally disabled person includes those like Sandra with Down's syndrome and other genetic conditions, plus those whose cognitive functioning has been damaged by accident or disease.

Sandra lives in her own apartment and cooks her own meals. She has cofounded two advocacy organizations for disabled people and speaks to a variety of audiences about disability awareness and other related issues (Fremon 1996, 18).

Many people with Down's syndrome develop coronary problems. In 1994, it was determined that Sandra was in congestive heart failure and needed a heart-lung transplant to save her life. Sandra was evaluated

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by the transplant committee at Stanford University. Following the meeting, she received a letter from the committee that included the following words: "...we do not feel that patients with Down's syndrome are appropriate candidates for heart-lung transplant."

Several months later Sandra and her mother went to the University of California at San Diego for an evaluation. Sandra received this letter from the UCSD transplant committee: "... Ms. Jensen is limited in her ability to have recall and memory. . . we are left with great concerns of her ability to not only adhere to the medical regimen required of her, but to understand the complexities of the transplant procedure... ."

Those who know Sandra understand that while she falls short on standard IQ tests, she has insights and wisdom as deep and meaningful as any other person. Her written reply to Stanford in-

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cluded the following sentiment: "I am saying loud and clear that I want the transplant. . . you must put me on the list now!"

Because of the efforts of her primary physician and family, as well as publicity, Sandra received the transplant at Stanford in January, 1996.

Transplant committees have an extremely difficult task in deciding who will benefit from a scarce resource, a donated organ. These decisions can mean the difference between life and death for the patients involved. Committees walk a tightrope in the name of justice, seeking a decision based on objective criteria that are as fair as

possible. When the supply of organs does not meet the demand, this task is even more daunting.

Included in the criteria, however, is the voice of the patient. In Sandra's case, it seems the committee did not listen adequately. Their accurate assessment of Sandra's understanding of the procedure — the risks, the burdens, and the benefits — seemed clouded by the fact that Sandra had a disability, when in fact she was aware of the difficulty of the convalescence and the dangers inherent in the complicated procedure. In spite of these difficulties, Sandra wanted a chance at the kind of life the procedure would allow her. Vital information, it seems, was lost or not listened to in the decision-making process.

Case Example — Robert

Robert was an eighty-six-year-old man with developmental disabilities. He lived at a developmental center for thirty-five years. Robert's cognitive impairment affected his ability to process information. He was able to express simple preferences — "brown bread and strong black coffee" — and could make his basic needs known, but he was unable to understand the risks and benefits of various forms of medical treatment. Robert loved music and enjoyed playing the piano. He outlived all of his family and had no available surrogate decision makers.

In the last year of his life, Robert became progressively weaker, moving from being ambulatory to wheel chair dependent, and finally to being bed bound. Robert's body was wearing out. The staff caring for Robert began to have questions concerning the aggressiveness of the care Robert should receive. What about CPR? Should Robert have a DNR order given the weakening condition of vital organs? Should he be transferred to an acute hospital for high technology intensive care or be kept at the developmental center and be given the finest palliative care available in familiar sur-

roundings?

Robert's caregivers brought the issue before the center's multidisciplinary bioethics committee. An immediate concern was that no family member was available to act as Robert's surrogate. The bioethics committee involved the regional center (Robert's legal conservator) and held a meeting with all those involved in Robert's care in attendance. Those who had known Robert the best told the committee the story of his life. Committee members engaged in conversation about Robert's medical condition and his preferences, including the activities he enjoyed.

Using this information, the committee formulated a recommendation that Robert have a no-CPR order and that he not be transferred to an acute hospital but receive palliative care at the center. The regional center signed the recommendation as the legal representative, and the physician wrote the DNR order. Robert stayed at the center and died peacefully, being cared for by those who loved him.

Informed Consent as It Relates to Patients with Developmental Disabilities and Mental Retardation

The concept of informed consent has evolved over the past eighty-two years through a variety of court cases. The reasonable person standard currently favored by courts requires that a physician disclose information concerning treatment options based upon the patient's need to know (Goldworth 1996, 216).

Appelbaum et. al. expand the strict legal requirement to include practical considerations for clinicians. For the proper exchange of information to occur so that the patient can make an informed decision, the patient must have the ability to:

- Communicate a choice;
- Understand relevant information about the treatment option;
- Appreciate the situation and the consequences of treatment;
- Rationally manipulate information (Galen 1993, 362).

Putting the concept of informed consent into clinical practice with persons who are mentally retarded can pose a particularly difficult challenge.

People with developmental disabilities possess a wide range of cognitive functioning, from those who were never competent or currently have no ability to process information, to those with marginal and transient decision-making capacity, to those who have the cognitive understanding necessary to give informed consent.

These patients also may or may not have the cognitive ability to process medical information in order to make an informed choice. Morris et. al. found this to be true when they used vignettes in a structured interview format to determine the capability of patients with mild or moderate mental retardation to give informed consent. "Several cognitive limitations seemed to underlie difficulties in expressing a rational decision, including deficits in memory, comprehension, and inferential reasoning" (Morris 1993, 269).

This study points out the need to work carefully with patients who have cognitive deficits. Assessing decision-making capacity for these patients is a time-consuming process. Patients with impaired judgment will necessarily need the advocacy of family or others who can accurately articulate the patient's values and preferences. There is a need to balance protection from harm with the patient's right to self-determination. This balancing requires skilled listening, the proper level of advocacy from caregivers, and pragmatic models of shared decision making.

Mark Kuczewski argues that the concept of informed consent based solely upon the individual patient and individual rights must be expanded to include the patient's family: "Informed consent should be seen as a process of shared decision making in which the thinking and values of the patient and health care provider gradually take shape" (Kuczewski 1996, 32). Providers often must look to those who can accurately translate the patient's values into treatment choices or share family values for patients who have never had

decision-making capacity.

On the one hand, it seems clear that Sandra Jensen possesses the ability to give informed consent. She understood the consequences of the options she was offered and she evaluated those options based upon her values, her great desire to live, and to continue to be an advocate for disabled people. Sandra expressed her desire to have the transplant based upon the information she received from her physician, thoughtful reflection, and the support of her mother. This is informed consent at its best, with Sandra undergoing the process of thoughtful, collaborative decision making, involving her family and health care providers.

Robert, on the other hand, never had the cognitive functioning necessary to understand that his body was wearing out. He knew he could no longer walk or do the things he enjoyed, but he could not consent to a no-CPR order. The case was complicated by the fact that Robert had out-lived his family, no appropriate surrogate decision maker was available. Robert's caregivers and the State of California had to decide what was in his best interest based upon what others knew of his values. Caregivers had to try to implement an appropriate ethical decision without activating the costly and time-consuming process of petitioning a court for judicial review.

The Due Process in Competence Determination Act (Senate Bill 30)

This law went into effect on January 1, 1996, in California. The bill provides specific statutory language to assist health care providers and the courts in making determinations regarding the decision-making capacity of patients to consent to treatment. A patient has the legal capacity to make decisions regarding medical treatment if they can do all of the following:

1. Respond knowingly and intelligently to questions about the treatment
2. Participate in the decision by means of a rational thought process
3. Understand the nature and seriousness of the

illness, disorder or defect, the nature of the medical treatment, the probable degree and duration of any benefits and risks of treatment, and the nature, risks, and benefits of any reasonable alternatives

Some people have criticized the Due Process Act because it includes a dramatic shift in legal perspective, from the notion that a person has decision-making capacity until proven otherwise, to an explicit presumption of incapacity to make decisions until proven capable through the above criteria. This concern is being addressed by a conference committee of the legislature that will propose amendments to the law.

The value of this legislation can be seen in the attempt to tackle the complicated issues surrounding determination of capacity for making medical treatment decisions. The Act's specificity and sensitivity are useful tools for clinicians: "The mere diagnosis of a mental or physical disorder shall not be sufficient in and of itself to support a determination that a person is of unsound mind or lacks the capacity to do a certain act."

The law also outlines specific areas of cognitive functioning that clinicians should evaluate when determining decision-making capacity: alertness and attention, information processing, thought processes, and the ability to modulate mood and affect.

This legislative attempt outlining a process to determine capacity can be combined with structured interviews using stories, such as in the Morris study, to develop practical guidelines that enhance patient self-determination while also protecting patients who lack the skills necessary to make informed choices.

Decision Making for Those Who Lack Capacity: Best Respect and an Ethic Of Caring

Cases like Robert's, a person with mental retardation, without decision-making capacity, and with no available surrogate are some of the most difficult in clinical ethics. In the past the ethical/legal standards of substituted judgment and best interest have been used in these cases. Substituted

judgment attempts to discern the patient's preferences as if they were competent. The presumption is to state what cannot be known. Best interests are often based only on the efficacy of a medical treatment, without adequate consideration for patient values.

A more ethically appropriate course of action in these situations is to develop an ethic of caring in the context of showing the best respect for the patient's values and the patient's moral voice.

Susan R. Martyn points out that the use of a substituted judgment standard for a person who never had decision-making capacity is legal fiction. Substituted judgment would require a committee or a judge to make the decision a patient would make if they were suddenly competent (Martyn 1994, 196). The best interest standard utilized by some courts in these cases is too medically oriented and therefore fails to adequately address the idea of attempting to discover the patient's values.

Martyn argues for a new legal standard, best respect:

Best respect can be understood as a decision-making standard that rejects any result as inevitable, identifies a group of persons best able to collect the most relevant information concerning objective medical facts and subjective moral voice, and requires that this group meet with each other to maintain focus and correct understandings. (Martyn 1994, 203).

This type of consensus building should take place within the context of the patient's "community of care." This may be a developmental center or a group home in the community, or an independent living arrangement. It is essential for the patient who lacks decision-making capacity that a group, such as an interdisciplinary ethics committee, gather together those who know the patient's values for an informed dialogue concerning treatment decisions.

The concept of best respect should be broad enough to allow a family to request withdrawal

of artificial nutrition and hydration from a patient in a persistent vegetative state as well as inclusive enough to allow someone in the position of Baby K's mother¹ to request continued treatment for an anencephalic daughter because she values her daughter's profoundly diminished life.

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Implementing an Ethic of Caring And Best Respect

Recently there has been a legislative attempt in California to facilitate a process for ethical decision making for persons without advance directives who lack decision-making capacity and who have no available surrogates without having to go through the courts.

The legislature amended Section 1418.8 of the Health and Safety Code to include a provision for patients residing in skilled nursing or intermediate care facilities who cannot give informed consent to a proposed treatment option and who have no available surrogate decision maker. The procedure could easily be implemented by an interdisciplinary ethics committee:

- The physician determines that the patient is unable to understand the nature and consequences of the intervention and there is no available surrogate.
- The facility conducts an interdisciplinary team meeting to review the proposed intervention. The team shall include: the attending physician, a registered nurse with responsibility for

caring for the patient, other staff determined by the resident's needs, and where practicable, a patient representative (ombudsman).

- The review will include the physician's assessment, the reason for the proposed treatment, discussion of the patient's desires where known, impact on the patient's condition, and reasonable alternatives.
- The determinations made in the meeting are documented in the medical record and the team evaluates the decision quarterly.

The recommended procedure in Section 1418.8 is similar to the protocol for case consultation developed by the bioethics committee at California's Fairview Developmental Center in March of 1992. The guidelines for the Fairview Center follow.

Bioethics Committee Guidelines for Case Consultations

The bioethics committee will use the following guidelines when the committee is asked to provide case consultation where decisions are being considered to limit life-sustaining medical treatment. It is the responsibility of the program director or their designee to see that the following information and personnel are present at the bioethics committee meeting.

1. The attending physician will provide written evidence of the client's medical diagnosis, condition, and prognosis, along with a current treatment plan. The attending physician will provide copies for the entire committee.
2. If family members are available they will act as surrogate decision makers for the client. Reasonable effort shall be made to reach a member of the client's family. Family members will inform the committee of their understanding concerning withholding or withdrawing life-sustaining treatment. If family members are not available, then a legal representative (the medical director or designee) will be present to assure that any recommen-

dations that the committee formulates are in the best interest of the client using a burden/benefit ratio.

The committee will assure that the surrogate decision maker has been fully informed by the attending physician of the consequences of withdrawal or withholding of life-sustaining treatment.

3. Appropriate residence staff will provide the committee with their understanding of the client's overall condition and the client's preferences. This should include but not be limited to: the client's group leader, unit supervisor, and program director.
4. The committee will formulate recommendations based upon all of the previously mentioned information, which will become a part of the client's medical record.
5. The attending physician will write an order in the medical record of the procedure(s) to be withheld or withdrawn.

New York State has formalized a nonjudicial approach to decision making for patients who lack capacity and who have no available surrogates. The Surrogate Decision-Making Committee program works in making health care decisions for persons with mental disabilities. The SDMC program uses panels of four volunteers to make decisions about proposed treatments. Each panel must contain a member from each of the following groups:

1. physicians, nurses, psychologists, or licensed health care professionals;
2. former patients or parents, spouses, or advocates of the disabled;
3. attorneys;
4. other persons with expertise in mental disabilities (Herr 1994, 1019).

The members of the panel conduct discussions based upon any evidence of preference expressed by the patient, as well as a careful analysis of the burdens and benefits of the proposed treatment options.

In Colorado, the Denver Community Bioethics Committee meets monthly and remains on call to review ethical issues in adult protection and long-term care settings involving residents or patients who lack decisional capacity (Mason 1995, 284). The committee is comprised of twenty-four members including social workers, nurses, attorneys, physicians, and clergy. In three years from 1992-1995 the committee reviewed thirty-five cases.

These approaches make the best of a difficult situation by seeking to discover patient values and preferences as well as locating surrogates. A synthesis of the California, New York, and Denver models could easily be replicated in communities where appropriate people are willing to serve on community based decision-making committees.

The new model would include important elements from each approach. Taking the detailed competency determination from California along with the community-based interdisciplinary committee used by New York and Denver could save time in probate court.

- There could be a determination made by an interdisciplinary team that the patient is not able to make medical decisions (California Senate bill 730), and that there is no available surrogate (section 1418.8) after reasonable steps have been taken to locate a surrogate.
- Ideally, each long-term care facility would have a surrogate decision making team with volunteers, including physicians, nurses, psychologists, advocates, attorneys, and persons with expertise in mental disabilities. The committee would seek to determine the patient's values when possible.
- If each facility could not have a committee, perhaps a local (Denver) or regional (New York) committee could be developed.
- The committees' case consultations would be reviewed and changes made as necessary.

Future Considerations

Community Placement/Aging Population

Many states, including California, are moving developmentally disabled persons out of large developmental centers and into small group homes within surrounding communities. As is the case with the general population, many of the people moving into the community are part of the Baby Boom generation (born 1946-1964). These people are getting older and will also be facing the chronic illnesses that affect older people.

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As Baby Boomer-generation parents pass away, there will be a lack of surrogates for medical decision making. To compound this, small group homes also lack the interdisciplinary staff necessary to establish an ethics committee. It is important that some type of formal procedure be established so that decisions concerning life-sustaining treatment can be properly reviewed for the clients who have no available surrogate decision makers living in small group homes.

In California, this could be accomplished through the Regional Center system. Each Regional Center could establish an ethics committee and develop protocols for case consultation to consider life-sustaining treatment by combining the best aspects of the SB730 and the revision of Section 1418.8 of the Health and Safety Code and crafting appropriate policies and procedures.

Advance Directives and Persons with Developmental Disabilities

Since the implementation of the Patient Self-Determination Act (PSDA) in 1991 and the media attention given cases such as Nancy Cruzan², more and more families of residents in developmental centers are raising questions

concerning life-sustaining treatments. As the public's awareness of advance directives has grown, we have seen an increase in requests from families at Fairview to complete advance directives on behalf of family members. Parents are disappointed to find out that they cannot execute an advance directive on behalf of their child. A common query is, "If I can fill a living will out for myself, why not for my daughter?"

It is ethically defensible to withhold or withdraw life-sustaining treatment from a noncompetent patient using proper safeguards; it is never ethically defensible to use the same procedure to euthanize people with serious disabilities.

The PSDA has backed us into an uncomfortable ethical corner. We encourage people to complete advance directives in order to enhance autonomy and assure surrogates are carefully selected and values documented, but we do not accompany this with a provision allowing families of persons with mental retardation who do not have decision-making capacity to exercise the same right on their children's behalf. This is an important ethical issue for developmental centers across the country.

As parents grow older, they fear that when they die there will be no one left to articulate adequately what is in the best interests of their children. In seeking to comply with the spirit of the PSDA at Fairview, we encourage parents who raise the issue of advance directives to write a letter expressing their values and concerns. This letter is placed into the person's permanent record. While this letter does not have the legally binding force of a statutory advance directive, it can provide guidance to health care providers

seeking to provide treatments that are in keeping with the patient's values. We need to develop a legal mechanism for parents to document values to assure their wishes are carried out after they die. If we are to adopt and implement the best respect standard regarding ethical decision making for persons with mental retardation, then we are going to have to develop an instrument to convey each person's moral voice (Beltran 1995, 102).

Physician-Assisted Death

A recent successful voter initiative (Oregon) and court decisions (2nd and 9th Circuit of Appeal) may allow states to craft legislation to permit physician-assisted death (PAD). The court decisions and initiative are careful to point out that PAD is only intended for patients with decision-making capacity. Decisions to limit life-sustaining treatment originally applied only to patients with decision-making capacity and then were extended to surrogates through court decisions and through the Patient Self-Determination Act.

Historically persons with disabilities have been devalued by society. The developmentally disabled who have never had decision-making capacity and have no available surrogate are at risk because others (often the state) are making decisions about the quality of their lives. These patients have no way to express their values and preferences. Because they are vulnerable and their care is expensive, PAD should never be an option for these patients. Comprehensive palliative care should be the standard of care for seriously ill disabled patients.

If efforts to legalize PAD are found to be constitutional, there should be a provision to assure that PAD can never be chosen by a surrogate for a person who is mentally or developmentally disabled. It is ethically defensible to withhold or withdraw life-sustaining treatment from a non-competent patient using proper safeguards; it is never ethically defensible to use the same procedure to euthanize people with serious disabilities.

Conclusion

Determining decision-making capacity for developmentally disabled patients must include a process that takes seriously the wide range of abilities of these people. The process should include a presumption that a patient has decision-making capacity unless proven otherwise. The listening process will require diligence on the part of health care providers.

Treatment decisions for patients without decision-making capacity and without available surrogates are currently being made by ethics committees, community-based committees, and state-authorized committees. The models cited in this paper could be drawn together into a synthesis that could be replicated in other communities.

Finally, those who work with the developmentally disabled need to develop a method to formalize family values by means of a legally recognized advance directive.

Advocates for the disabled will also have to work to assure that if and when physician-assisted death is a legal option, it is never permitted to be an option for vulnerable, disabled people who do not have the ability to speak for themselves.

One need only look to the Netherlands where PAD and euthanasia, though illegal, are practiced and physicians are not prosecuted if guidelines are followed. This is important because confirmed reports from the Netherlands document that the practice of PAD and euthanasia that began only for competent adult patients, has expanded to include, for example, a woman with no physical illness who was clinically depressed, and severely handicapped newborns who cannot speak for themselves. PAD clearly puts the disabled at risk (Gevers 1996).

Endnotes

1. Baby K was born in Virginia with anencephaly. During her two years of life she intermittently required respiratory life-support. During this time, Baby K was kept alive at the insistence of her mother and against the recommendation of the hospital and attending phy-

sicians.

2. In 1983 Nancy Beth Cruzan was injured in an auto accident that left her in a persistent vegetative state. In their attempt to discontinue life-sustaining treatment for their daughter, her parents took their case to the Supreme Court.

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