

ETHICS IN THE CONTEXT OF DISABILITY

Margaret Somerville

Introduction

What is ethics?

In everyday language ethics can be described as trying not to do the wrong thing in the sense of harming people, first do no harm, and, then, wherever possible, doing the right thing in the sense of benefiting people.

Ethics is about values, especially shared values, in particular those we adopt as our basic societal values – they are sometimes called norms. The nature of a value is not easy to define. The Oxford English Dictionary defines it within the context of ethics as: “That which is worthy of esteem for its own sake; that which has intrinsic worth”. Another way to describe values might be as “ethical organising principles” – they are principles that we can use to guide us in deciding what is ethical and what is not. For instance, a belief that it is wrong to discriminate against people on the basis of physical or mental disability is a value. Applying that value in practice allows us to identify both what we must not do to people with a disability and what we must do for them.

Individual values and our conduct in individual cases, on the one hand, and societal values and our conduct as a society, on the other, are linked in both directions. Societal values, especially when

enacted as law, govern how we may, must, and must not treat individuals. And what we do in an individual case - for instance, how we treat a person with a disability - establishes, affirms or detracts from societal values. So, for instance, if we withdraw a feeding tube from a person with a disability without the same justifications that would be required to allow its withdrawal from a person who is not disabled, we are establishing values in our society that people with disabilities have lives not worth living, that they are of less value than the rest of us.

One person I will discuss in this chapter is Terry Schiavo, a woman in a coma who has been at the centre of a legal storm of whether the feeding tube through which the hydration and nutrition that are keeping her alive are delivered, may be withdrawn. Her situation provides a good example of how we go about an ethical analysis and how it is not only the end results that count - that is, whether or not the feeding tube is withdrawn - but also, the reasons and the justifications that we have for our decision to retain or withdraw it.

“Doing Ethics”...

I call the process of undertaking an ethical analysis “doing ethics”. An important methodology in doing ethics is engaging in “ethics talk” or an “ethical conversation” with all the people who should be involved in making a certain ethical decision.

Doing ethics consists, first, in identifying all the ethically relevant facts. Good facts are essential to good ethics. Second, we must identify the values that are in play in the situation. Sometimes we can do that for ourselves, other times, we need an ethicist to help us to identify the full range of those values. Third, we must see whether any of these values are in conflict; if they are not, we do not have an ethical dilemma because we can honour all of them. If there is conflict, however, we must prioritize our values and that is where we often do not agree. Not everybody gives the same weight to the same values or chooses the same order of priority when they are in conflict. Finally, and this is the most important aspect of doing ethics, we must justify the priority that we choose when not all values can be honoured. That justification is the essence of doing ethics.

MAKING ETHICS DECISIONS:

- 1. Identify all ethically relevant facts.**
- 2. Identify values.**
- 3. Identify any conflicts of values.**
- 4. Prioritize conflicting values.**
- 5. Ethically justify the priority adopted.**

For example, Granny is subscribing to dozens of expensive magazines which she just glances at and throws away. She is depleting her small but otherwise adequate financial resources. These are the ethically relevant facts. The values in conflict here are respecting Granny's autonomy - her right to decide for herself, in

this case her right to do what she likes with her money - and protecting her financial well-being. Assuming that Granny is mentally competent (and making what others regard as foolish decisions does not mean that she lacks mental capacity, moreover, there is a presumption that all adults are competent, unless the contrary is proven) she has the right to decide for herself what to do with her money, that is her right to autonomy must be respected. If she is not competent, we may disagree on which value should be given priority. We should start from a presumption of respect for Granny's wishes and, unless doing so would seriously harm her, they should be implemented. Harm includes the insult to her dignity in going against her wishes, and depends on the overall impact the magazine subscriptions have on her financial well-being and what she may lose as a result - for instance, access to other activities that give her great pleasure. To justify not following her wishes, the harm to her dignity in over-riding them and in her not receiving the magazines must be clearly outweighed by the benefit to her of protecting her financially. Importantly, the reason for this choice must be solely to act in her best interests and the decision maker must have no conflict of interest.

Or, again, we can take Terry Schiavo situation as an example. The facts are in dispute there. Is she or is she not irreversibly comatose? Should the arguments of those who believe that it is undignified to keep alive a person in a irreversible coma by the

delivery of hydration and nutrition through a feeding tube prevail? Or should the value of respect for life and our obligations to support the lives of those who are unable to decide for themselves because of disability - in this case, mental incompetency - take priority? I discuss below the way in which we can analyse this values' conflict, but before doing so, I want to introduce you to some general concepts that are important to keep in mind in considering the ethics of any situation in which doing so is relevant. These concepts can help to make us aware of factors, that we might otherwise overlook, that can strongly influence our decisions about ethics. They are important in doing ethics in general, but especially in the context of ethics in relation to the treatment of people with disabilities.

Concepts

i. The importance of language...

Language - and within that concept, I include words, metaphors and analogies - is never neutral and our choice of language influences our decisions. For instance, it makes a huge difference whether we describe euthanasia as "a merciful act of clinical care" or "the last act of good palliative care", on the one hand, or "killing the patient", on the other.

A recent advertisement showed a young man and a young woman, one of them a person with Down syndrome. It was entitled

“Different genes. Same value.”¹ The advertisement described “Today’s Reality” of the discrimination against people with Down syndrome and their lack of opportunities. It also outlined “Tomorrow’s Dream: [that] every baby born with Down syndrome, or any other difference, will be celebrated not mourned. ... Every Canadian will be valued for their uniqueness, their differences and their common humanity”. This is the language of respect, equality and difference, not disrespect, denigration and inferiority; the language of shared citizenship and humanity, not of depersonalization, isolation and exclusion.

There is a saying in ethics, that “we ignore our feelings at our ethical peril”, because feelings can give us access to deep moral intuitions that are otherwise inaccessible. But our feelings, and therefore our moral intuitions and emotional responses, are affected by the language we use to describe people or situations. The danger is that our feelings can be wrongfully manipulated through choice of language and, as a result, we act unethically.

Amy Hasbrouck, a disability rights lawyer, who is also a person with a disability, points out that, as well, people can have an instinctive reaction to disability itself, quite apart from the language used to describe it:

I think disability affects non-disabled people on a very instinctual level, and it can be a negative effect.

¹ *The Globe & Mail* (Toronto), November 1, 2003, A10.

People tend to shun and exclude those members of the community who are perceived as weak for many reasons. Beginning with a simple "us/them" dichotomy, non-disabled people add valuation based on fear, of the unknown, contagion, weakness, loss of control, ostracization, and loss of status. So aside from the distorting effects of language, for humanity to evolve to the next level of consciousness (as you describe at the end of the chapter) we must overcome our "gut" revulsion and assign a positive value to difference.²

ii. The misuse of concepts...

Respect for human dignity is often put forward as the primary value that should govern both birth and death. In the 21st century, that translates to the values that should govern the new genetics and the decision about legalizing euthanasia. But there are dangers, not always recognized, in using the concept of dignity.

There are two versions of this concept - *intrinsic* human dignity and *extrinsic* human dignity - the applications of which can have radically different outcomes.³ Intrinsic human dignity means

² Personal communication, 31st December, 2003.

³ Margaret Somerville, *Death Talk: The Case against Euthanasia and Physician-Assisted Suicide*, McGill-Queen's University Press; Montreal, 2001. See also S. D. Stolberg, "Human Dignity and Disease, Disability, Suffering: A Philosophical Contribution to the Euthanasia and Assisted Suicide Debate,"

that every human being is seen as having innate human dignity which must be respected. At a minimum, it requires respect for the life of the person. Extrinsic human dignity focuses on the “quality of life” of the person and, if this is perceived to be below a certain level, the person is regarded as lacking dignity. Proposals to remedy situations of a perceived lack of dignity include, for instance, discarding human embryos with a genetic “abnormality” such as Down syndrome,⁴ or euthanasia in the case of a person who is terminally ill,⁵ in both cases in order to respect such dignity as they may be deemed to have. But that is to accept that life, itself, is an affront to their dignity and, therefore, that eliminating them does not contravene their dignity, indeed, it is to implement respect for it. In short, the claim is that we respect the dignity of the future person the embryo would become - and who now will never exist - by ensuring that the embryo does not survive. To say the least, this is convoluted reasoning.

Concepts such as human dignity and quality of life were originally formulated in order to protect human life.⁶ They provided a basis for people’s claims that they had a right to be treated in certain ways or to receive certain care or treatment; denial of such treatment would amount to a failure to respect their dignity

abstract, *Humane Medicine* 11 (1995), pp. 144-7.

⁴Margaret Somerville, *The Ethical Canary Science, Society and the Human Spirit*, Viking/Penguin Canada; Toronto, 2000, pp. 29-30.

⁵Somerville, *supra*, note 3.

⁶Somerville, *supra*, note 4, p. 167.

or to fulfil an obligation to ensure a minimally adequate quality of life. In contemporary society, however, the concepts are often used to the opposite effect: to argue, for example, that a person's quality of life is so low that it does not merit either protection or the cost of support; or that continuing to live is an affront to the person's dignity and therefore the person's life should be ended.⁷ The notion of *intrinsic* human dignity cannot be used in this way, however; it requires respect for all humans and for human life as such.

Because of the ambiguity of the concept of respect for human dignity and its potential for misuse, we should not use it as a substitute for the concept of respect for human life, although it can have value when used as a secondary or back-up concept to the latter.

iii. Characterization of actions...

Yet another related feature of "doing ethics" is the use of concepts to characterize our actions in certain situations that raise ethical difficulties, in ways that directly result in our seeing what we are doing as either ethical or unethical. We must be aware of the need to be ethical in our use of such concepts and, once again, of how these characterizations can affect our moral intuitions and, consequently, our decisions.

⁷ Somerville, *supra*, note 3, p. 334.

For instance, one distinction that was used in the past to classify treatments that must be offered to people, as compared with those which need not, was the treatment that was *ordinary* or *extraordinary*: Ordinary treatment must be offered, extraordinary treatment need not. The problem is, however, that sometimes it is not the treatment that is classified as ordinary or extraordinary, but rather the person who is to receive it. For instance, when physicians were asked in a survey whether they believed that a relatively simple operation on a child to correct duodenal atresia - a blockage of the child's duodenum which the child was born with which meant the child could not digest any oral nourishment - was ordinary treatment, the vast majority of physicians classified it as such when the newborn baby did not have any genetic abnormality or serious medical condition. The same physicians saw that treatment as extraordinary when a child with Down syndrome was the patient.

A similar response can be seen in with regard to the concept of futility. Treatment - for instance, giving an antibiotic - is characterized as futile and, therefore, need not be provided, when it is being considered, for example, for a person in a irreversible coma, but as non-futile when the person has the same condition - for instance, pneumonia - for which the treatment is indicated, but is not in a irreversible coma . Another misuse of the futility concept is to require that a treatment must "improve" the condition of the

person receiving it, if it is not to be deemed futile. This can often preclude "maintenance" treatments, of especial concern to people with chronic disabilities who may never "get better". Such treatments for these people may be classified as futile with the result that there is no obligation to provide them. A much less open to abuse and much more precise concept of futility is that of "medical futility", which applies equally to both people with disabilities and people without disabilities. This asks whether this treatment is medically futile for this person, that is, will have no useful medical effect. If there would be no such effect, the treatment may be withheld as being futile. If the treatment is not medically futile it cannot be withheld on the basis of futility, although there could be other justifications for withholding or withdrawing it, for example, its burdens for the patient far outweigh any possible benefits or the patient refused it while competent through an "advance directive".

Yet, another example of the same characterization phenomenon is whether we see hydration and nutrition delivered through some technological mechanism, whether a feeding tube or intravenously, as food and water which we would regard as not being justifiably withheld, or artificial hydration and nutrition treatment, which, like other life support treatments, can be justifiably withheld in some circumstances.

iv. Basic presumptions...

We often fail to recognize the importance of basic presumptions in our decision-making. There are four possibilities. *No*, for example, people with disabilities will not have access to certain treatments. *No*, they will not have access *unless*, for instance, they can prove special needs. *Yes*, they will have access, *but* not if the cost is more than the government believes it is reasonable to pay. Or *yes*, they will have access. Ethics must guide our choice of which of these basic presumptions should apply in any given situation to any particular individuals and a wide range of ethical and other considerations must be taken into account in making that choice. I will discuss only one such aspect here.

Many people do not recognize that there is a major difference between a *no, unless* presumption and a *yes, but* one. From an ethical perspective, however, it is important to be aware of that difference. In conditions of equal doubt as to what should happen - for instance, whether people should be given access to certain services - a *no, unless* presumption means that the person will not have access, whereas a *yes, but* one means that they will. That difference occurs because in situations of equal doubt, the basic presumption governs. In *no, unless* that presumption is no; in *yes, but* it is yes. Consequently, the way in which legislation, regulations or guidelines are framed can have a major impact on, first, whether or not services are provided and, second, in

conditions of equal doubt as to whether or not they should be, who has the burden of proving that. In a *no, unless* situation the person needing the services must prove their entitlement; in a *yes, but* situation, the person denying services must show they are justified in doing so.

v. Vulnerable populations...

The ethical principle that we should make decisions on the basis of a preferential option in favour of people who are most vulnerable should be applied where there are conflicting values or claims, unless there are good reasons to the contrary. In other words, when we must choose between the rights and claims of people who are more vulnerable and less vulnerable ones, we should choose in favour of those who are more vulnerable.

Vulnerability is also ethically relevant in another way. We may only involve people who are vulnerable in risk-taking activities such as medical research, if it is not possible to carry out the research on people who are less vulnerable. In short, people who are vulnerable are entitled to greater degrees of protection than less vulnerable ones. On the other hand, we must be careful that in applying these principles we do not engage in unacceptable paternalism or, as discussed previously in relation to other concepts, wrongfully use them with the result that rather than protecting the people they were intended to benefit they harm

them. For instance, it would be unethical to deny people who are vulnerable access to an apparently superior treatment that became available on the grounds that it was research and, therefore, people who are vulnerable should not be involved, when the real reason it is being denied is its expense.

Vulnerability is yet another concept meant to protect people that can be misused. There is an old saying, that nowhere are human rights more threatened than when we act purporting only to do good. Often that occurs because our desire to do good blinds us to the harm that necessarily also accompanies our actions. Sometimes, however, we want to “do good” for self-serving reasons. For instance, some health care professionals or institutions fail to respect the autonomy of people with disabilities. They argue that they should decide on the type and timing of care, because only they are qualified to provide it to people who are “vulnerable”. Such arguments are sometimes based, however, in such people’s concerns to maintain their jobs or institutions’ their viability, rather than on what is best for people with disabilities and most respectful of them.

Being able to choose the risks we will run and those we will not is at the heart of individual freedom. People who are not disabled have that choice within the limits of the public policy that applies to everyone. People with disabilities should be no less free.

The presence of choice, even if it is not exercised, matters in creating a sense of freedom. Indeed, because people with disabilities experience some unavoidable losses of freedom as a result of their disability, they should be regarded as having stronger claims than others not to have the freedoms they can enjoy interfered with.

Such an approach is important not only in major public issues, such as formulating legislation, but in small everyday matters, such as choosing one's caregiver or the type of care one receives. Some people with disabilities may choose institutional care, but others who wish to do so should be funded to employ people of their choice from the community, who will provide the support needed.

Hasbrouck sums it up this way:

Disability as a basis for oppression is an area where ethics arises at times. Few people, even members of other "minority" groups, understand disability as a civil rights issue, probably because of the "special privileges" accorded to people with disabilities. I'm sure women had similar problems when fighting for equal rights, trying to point out that the mantle of protective paternalism was itself oppressive, and concealed greater violence and subjugation. So people with disabilities are trying to point out that maintaining paternalistic benefit policies which keep people with disabilities at or

below the poverty line, and make it difficult to accumulate adequate resources to make the leap to full employment, are ultimately more limiting than helpful. Policies created to "protect us" (such as requiring that those who provide assistance with activities of daily living have medical training), may prevent us from taking necessary risks to live independently.⁸

vi. 21st Century birth and death and the effects on people with disabilities...

The two great events in each human life, birth and death, have always been the focus of our most important individual and shared values. Reprogenetics (reproductive and genetic technologies) have radically affected the possibilities at birth; a similar change has taken place in relation to death with the "pro-legalization of euthanasia" movement. The latter, in contrast to the former, does not result, however, from the advent of any radical new technology affecting death; indeed the contrary is true, there is now much more that we can do to relieve the suffering of dying people than we could in the past.

The use of the new genetics - the possibility of pre-implantation genetic diagnosis and pre-natal diagnosis to detect and eliminate genetically 'defective' embryos and fetuses - sends

⁸ Personal communication, 15 November, 2003.

multiple messages of relevance to people with disabilities and has major impact on societal values. Embryos and fetuses are destroyed on the basis of their having conditions with which people with disabilities live their lives. These embryos and fetuses are seen as defective, their lives not worth living, and the avoidance of the suffering life would involve for them – which is a subjective, value judgement on the part of the decision maker – is viewed as justifying their destruction. In the context of abortion on demand – that is, abortion is not seen as requiring any ethical justification and there are no legal restrictions – not surprisingly people are often incredulous that one would have ethical concerns about eliminating embryos or fetuses for “good” reason, that is, they are ‘defective’. It is not difficult to see why *writ large* (that is, applied as general principles at the level of societal values) the messages about values that these practices communicate are of deep concern to people with disabilities. The scientists, physicians and genetic counsellors using the new genetics hasten to assure them, however, that what is done to embryos and fetuses does not set any precedent for what might be done to them. It is difficult to understand how they can be so reassuring. As Hasbrouck wrote to me, “ People with disabilities [must] try to get the message out about the slippery slope between assisted suicide, euthanasia and eugenics”⁹.

The connections and interactions between technology, societal

⁹ Ibid.

attitudes and values, our perceptions of what it means to be human, and the meaning of human life are complex¹⁰. Features of post-modern societies such as Canada include an emphasis on rights, intense individualism including intense moral individualism - “my values are no one else’s business and certainly not the business of the State” - and valuing people not just simply because they exist but for what they can do. We have become “human doings” and assessed as such, rather than human beings. The next move in the transformation of humans could be from human doing - which at least still retains the basic integrity of human nature - to human technological product. That might seem unlikely at first glance, but there are strong indications that we are starting to see ourselves in that way. For instance, young people see technology such as cell phones as an extension of their ear, that is, as part of themselves, whereas older people see them as a separate piece of technology.

Human reproduction is becoming increasingly technologized and people are looking to use reprogenetics (the combination of reproductive technologies and genetics) to choose the features of their children, first, in terms of avoiding illness or suffering for them, and, secondly, to enhance them, whether mentally - for instance, in terms of intelligence - or physically. The trans-humanists are unreserved advocates of such possibilities. They

¹⁰ Margaret Somerville, *The Ethical Canary: Science, Society and the Human Spirit*, Viking/Penguin, Toronto, 2000.

believe that we will become “post-human”, that is, *homo sapiens*, as we know ourselves as a species, will become obsolete, because what will amount to a new re-designed species - post humans - will become the norm. These emerging situations can provide important insights relevant to people with disabilities that point to developments which should be of concern to them.

We see here an intolerance and devaluation of difference, a search for the perfect human and an assumption that we can define what that is and then create humans to that pattern. We see the taking of control in situations that used to be matters of chance, such as that each individual’s genetic inheritance can now be chosen by others who act under an assumption that they have the right to design future generations of humans. This is a move from chance in the great genetic lottery of the passing of human life, to the choice of present generations with respect to the genetic inheritance of future generations. It is a 21st century version of slavery as those people who are designed by others can never be equal to their designers or free in the sense that they are truly a child of nature and the universe. Someone else - another or other humans - owns their origins in a way that means they can never fully own themselves.

Moreover, there is an assumption that those who cannot be made “perfect” may alternatively be discarded as embryos or

fetuses or used for some “useful purpose”, that is, be made of benefit to others through being used in medical research or for the harvesting of stem cells for the production of therapeutic products, tissues or organs. These matters may seem far removed from the everyday lives of people with disabilities, but they are very important to keep in mind, because how we deal with them will set important values and precedents that will have major impact on people with disabilities of the future and the way in which they are treated by society.

What can we do to arrest this loss of respect for every human life and for its uniqueness, this trend towards a technological fix for all perceived problems and, accompanying that, the phenomenon of turning mysteries - whether the mystery of life or the mystery of death - into problems, especially medical problems, and then seeking a technological, especially a medical technology, solution to that problem?

vii. Presumption in favour of the natural and Nature

I propose that we must re-value the natural and Nature and our place in the natural world and the values that flow from it. This is not a Neo-Luddite (Luddites were late 18th Century people who saw the advances made possible by science and technology as evil. They smashed the machines that replaced them in their factory jobs. Today, the designation Luddite is used to describe people who

oppose the modernizing impact of technology.) or anti-scientific stance, and it is not an argument against reaping the benefits of the new science. Rather, it is to propose that we should work from a basic presumption in favour of the natural and, if we are to intervene in that, we must have justification for doing so. That justification must take into account not only physical harms and risks, but also moral ones, and not only harms and risks to present generations but also to future ones. Take, for example, the wider impact of the choice of individuals not to have children with a certain genetic make-up or certain conditions. What are the implications for people already living with those conditions? What does it mean that we do not expect parents to accept the children born to them and love them unconditionally, but only if they conform to a certain “standard” that they see as acceptable? And what about the cumulative effect of these individual choices that mean certain groups of people will be dramatically reduced in number or even eliminated from our society, for instance, people with Down syndrome, bipolar disorder (manic depressive illness), or achondroplasia (dwarfism)? Through the accumulation of individual decisions, we are creating a situation in society that would never be approved of as public policy, namely the elimination of certain groups of humans on the basis of their innate characteristics. And is it not just sophistry (an argument used intentionally to deceive or confuse) to argue that these are all individual decisions and, therefore, should not be looked at

cumulatively as the new eugenics?

This new eugenics is one more manifestation of the effects of taking an entirely individual rights focus to our use of the new technoscience. In this case, the rights of individual parents not to have a disabled child are given priority over any rights of the child to exist or protection of societal values. In short, individualization, personalization and privatization of the decision-making about reproduction, unlimited and unguided by any societal limitations, is giving rise to a new eugenics. And although these decisions are characterised as entirely private choice, they will necessarily give rise to *de facto* public policy. In particular, we must consider the impact that that will have on people with disabilities. At the least, it is likely to affect the self-esteem of people with disabilities and their perceived worth both in their own eyes and the eyes of others. In the context of acceptance of doctrines of quality of life and extrinsic dignity, it will be linked to a rising frequency of calls for euthanasia for people whose lives are considered not worth living. Euthanasia will, in turn, be seen as a largely acceptable response to suffering. All of these responses will be placed under a two-tone cloak of “doing good to the person concerned and doing that good through medical means”. A doing good medical cloak is very re-assuring for us that we are not doing bad.

viii. Religion...

The role of religion in the public square in 21st Century secular democracies is a controversial and complex topic. Suffice to say that state and church must be separate, but that does not mean that the views of citizens based on their religious beliefs are irrelevant in formulating public policy. Rather, as is true for all citizens, they have a right to be heard. Here, I want just to raise one issue that is relevant to people with disabilities and their views and rights to be heard in the public square, especially in relation to public policy that affects them directly.

Very often the views of people with disabilities, for instance their opposition to euthanasia or the abortion of fetuses on the basis of genetic “defects”, are equated to the views of people whose opposition to such practices is religiously based. People with disabilities are then grouped with the latter and, like them, their views are dismissed as irrelevant to public policy. This is an *ad hominem* (attacking the person themselves and not their arguments) approach of labelling one’s opponents in order to dismiss them and their arguments on the basis of that label, instead of addressing the substance of these arguments.

Hasbrouck sees this phenomenon from another perspective, that is, as the disability community being used to further yet another agenda in which their rights and needs are not the central concern:

One challenge for the disability community in doing this work [of protecting the rights of people with disabilities] is not to be out-shouted and outshone by the right-wing Christian "right-to-life" people who tend to treat us like poster children, ignore the oppression and equal rights aspects of the disability argument, and would restrict rather than reinforce individual liberties. They would co-opt folks with disabilities; many of us disagree heartily with their agenda. Yet the media are generally loathe to acknowledge that folks with disabilities have a distinctive perspective, and it's easier to go with the "sanctity of life" sound-bite than it is to convey the complex ideas embedded in the disability-rights argument.

The other problem here is that the religious communities are rich, and may be willing to provide funding where no one else will. ...Most left-wing, progressive organizations -- which would otherwise provide funding to a group like NDY [Not Dead Yet] -- have a knee-jerk reaction in favour of assisted suicide. Most liberals have bought the myth propagated by Hemlock and others that those who choose "death with dignity" really have "freedom of choice" and are exercising "self-determination." People are reluctant to look beyond their own fear of disability and loss of

control to analyze who is using the "service" and why, and to see that where people are confronted by lack of independent living services, capitation (setting an upper limit on the amount of resources that will be provided) of [US] medicare care, inadequate palliative care, architectural and attitudinal barriers, and other economic and social pressures, death seems the only viable option.¹¹

Sorting Out the Confusions in the *Terry Schiavo* case

I turn now to the case of Terry Schiavo, the disabled Florida woman at the centre of a legal storm over whether a feeding tube on which her life depends may be withdrawn. It shows the complexity of these decisions and the confusion that besets them. To respond ethically and formulate ethical public policy to govern such cases, we must identify and understand those confusions.

First, there is confusion about the nature of artificial hydration and nutrition and the act of withdrawing it. Because all of us as babies require someone else to provide us with food and water, withholding them has a special personal impact and also is highly symbolic. We rightly recoil from seeing ourselves as causing people

¹¹ Supra, note 7.

who are dependant on us for the necessities of life, to die of thirst or by starving to death. But, are food and water, on the one hand, and artificial hydration and nutrition, on the other, of the same nature? Likewise, the act of withdrawing each? And is tube-feeding “food and water” or artificial hydration and nutrition?

Then, the media often characterize the debate as a conflict between “sanctity of life” and a “right to die”. Both of those terms, and the differences between them, can lead to confusion.

Sanctity of life is strongly associated with religious objections to euthanasia. And some people who oppose withdrawing artificial nutrition and hydration do so for religious reasons and because they see it as euthanasia. But there are good secular reasons for such opposition, and many people who oppose euthanasia accept justified withdrawal of treatment to allow a person to die from their underlying condition.

Sanctity of life is also associated with vitalism, a belief that all life must be sustained for as long as possible. Because our bodies die in stages – death is a process not an event - this approach can cause problems. For instance, some people for religious or cultural reasons believe a person is not dead when the legal criteria for declaring their death - that is, brain death - are fulfilled. They want

all treatment continued on the “dead” person. Some opponents of the withdrawal of artificial hydration and nutrition, who are not vitalists, are labeled as such to dismiss their objections.

Sanctity of life can be contrasted with a less loaded concept of “a deep respect for human life”. The latter holds that acting with a primary intention to cause death, that is, euthanasia, whether through act or omission (sometimes confusingly called active or passive euthanasia - there is no ethically or legally relevant difference between them) is always wrong. But it accepts that allowing a person to die can be justified in certain circumstances - that is, there is both rightful allowing to die by withholding or withdrawing treatment and wrongful. And there is no ethically relevant difference between withholding or withdrawing treatment.

The term “a right to die”, as compared with “a right to be allowed to die”, causes confusion between euthanasia (including by wrongful withdrawal of treatment) and rightful (justified) withdrawal of treatment. A right to die includes euthanasia; a right to be allowed to die does not. Failure to provide treatment in order to allow a person to die - to “let nature take its course” - is not euthanasia when that decision is justified.

What are those justifications? One is that the person is dead.

There is no obligation to treat dead people. People who are brain dead are dead, so stories of people agonizing over withdrawing life support treatment from “brain-dead people” are confused. The confusion arises because permanent, irreversible loss of consciousness, that is, “upper brain death” as is true of Ms. Schiavo, but not of autonomic bodily functions such as spontaneous respiration, is mistakenly equated to “brain death”. Brain death requires irreversible cessation of all upper and lower brain function, which means autonomic functions, such as breathing, cease.

Another justification for withdrawing treatment is that the treatment is medically futile, that is of no medical benefit. A neurologist testified Ms. Schiavo’s upper brain “looks like a black hole”. Does that mean that all treatments are medically futile for her? But even if they are, is tube feeding medical treatment or basic care that must always be provided? And how should intravenous hydration and nutrition be characterized?

Other justifications include the person’s informed refusal of treatment, either at the time if the person is competent or in advance through “advance directives”. Or the treatment is so burdensome that its harms far outweigh any benefits it could provide. This justification raises difficulties because value judgments are involved and we do not always agree on the weighting or prioritization of values when they conflict, as the battle between Ms. Schiavo’s

husband and parents shows. And can people who are irreversibly comatose be said to experience benefits or suffer harms?

When the patient's wishes are not known, the legally authorized "substitute decision-maker" must step in. This person, possibly unlike Ms Schiavo's husband, must be free of conflict of interest. Most jurisdictions now require such decision-makers to act on the basis of what they believe the person would have wanted, were they able to decide for themselves - so-called "substituted judgment". When that is not possible, that decision-maker must act in the "best interests" of the person. These latter decisions are founded on a presumption in favour of life. Consequently, a decision to withdraw treatment and allow the patient to die must be able to be justified by the person making it.

We seem to have less trouble with withdrawing respiratory support than artificial hydration and nutrition. We see artificial respiratory support as needed to support a failed respiratory system and if that support is withdrawn, the person dies from the underlying cause, their inability to breath. The same description can be applied to the withdrawal of artificial hydration and nutrition. The person has a failed alimentary (food in-take) system and the withdrawal of artificial life support means the person will die from the underlying cause, their inability to eat and drink. In the case of withdrawal of respiratory support, we do not, however,

withhold air; the person just cannot use it. Similarly we must not withhold food and water that can be taken naturally. But what does naturally mean? When is food and water just that, and when artificial life support? Sometimes, as in the case of Ms. Schiavo's feeding tube, there is not a clear line.

As well, some bases for such decisions are unethical, or even illegal, for instance, withdrawing artificial nutrition because we see the person as having a life not worth living, or the decision constitutes discrimination on the basis of physical or mental disability. People with disabilities are deeply concerned that, as a society, we value people for what they can do, not simply because they exist – we see people as 'human doings' not human beings. To withdraw artificial hydration and nutrition because the person is no longer "a productive person" would be to set dangerous precedents for them. We must be concerned about the impact on people with disabilities and also on important values, especially respect for life, of withholding treatment from people who are highly vulnerable such as Ms. Schiavo.

Terry Schiavo has no upper brain function and is permanently and irreversibly unconscious. Any precedent her case sets must be strictly restricted to people in that state. She can be seen either as simply needing an alternative mode of receiving food and water because of her unconsciousness, or as having a failed alimentary

(food intake and digestive) system and needing life support treatment. If the feeding tube is basic care and simply a mode of delivery of "food and water" it must be maintained. If it is life support treatment for a failed alimentary system the question is: Are there justifications for withholding it? These are and should be difficult decisions. We must avoid confusion and choose the language that we use to describe her situation and treatment ethically, because it will radically affect how we see the ethics of maintaining or withdrawing that treatment.

Conclusion

To return, yet again, to the words of Amy Hasbrouck:

Many of the ethical issues related to disability lead back to a single assumption; that there is a norm for humanity and those who do not conform to it are less than, and must be a) isolated, b) limited, and/or c) disposed of. This comes up in every phase of life; genetic screening, Baby Doe cases, resource allocation questions, social response to abuse of people with disabilities, assisted suicide and end-of-life care. How we define who is "human" and "alive" is a cognitive, performance-based standard.¹²

¹² Supra, note 7.

We can best test the ethical tone of a society by how it treats its weakest, most vulnerable, most in need members, not by how it treats those who are powerful and able to care for themselves. Disabled people are rightly challenging our societies to see them as a test case for that ethical tone. We should understand the major, very broad and long-term impact, for good or ill, on some of our most important values of society's response to their challenge, even if we are interested from only a selfish perspective.