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Editor's Forum

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Two recent highly publicised cases of infants being totally dependent on life saving technology in ICU have produced massive media responses. In each case the “social media” played a major role in generating public discussion about the baby’s situation and the care being provided (*Edmonton Journal*, 2010; *The Globe and Mail*, 2011). The traditional privacy and confidentiality accorded to all patients in ICU was blown apart amid the intense media scrutiny. Each of the cases involved an infant who had been very ill and had experienced severe neurological impairment. Although very different in clinical detail, the two infant’s clinical courses highlight a new technology driven phenomenon in ICU with respect to life-sustaining treatments. These babies both arrived over a period of months at a stage of illness where no further improvement or deterioration appeared to occur. They both remained “stable on life support”. This prolonged stage of living on life support in ICU is common when a cure is the goal of therapy. However, for infants with likely fatal underlying illness, it is only possible by ongoing provision of care somewhere between full life saving and palliation.

Traditional ethical discussions in ICU about limitation or withdrawal of life supporting treatment when patients have incurable illness focus on the likelihood of imminent death or severe future disability as important considerations. These two infants remaining “stable on life support” blur the ability to be clinically certain about their dying and death. The conflict around these infants illustrates that beyond the narrow clinical criteria of dying and death lies a world of meaning, values and beliefs. As such, health care professionals and the public may

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learn from these heartbreaking cases to re-examine concepts of dying and death within a broader social context.

The papers in this issue of *Health Ethics Today* address living, dying and death from very different perspectives. Joffe's paper questions our traditional medical understanding and explanation of dying and death with reference to the clinical practice of organ donation after cardiac death (DCD). He argues in favour of a radically different understanding of what constitutes the dying process and declaration of death in the specific circumstance of DCD. Unless this occurs he insists that the DCD practice is not ethically acceptable and he calls for a moratorium on its undertaking in children.

Janz's paper reminds us that the so called "high-tech" life supporting interventions of ICU (highlighted in the two infant stories above) are also used in "low-tech" environments. Many individuals with disability live a happy day to day technology

dependent life outside the acute care system. She warns of the worry experienced by such individuals, when they enter the acute care system, that they will be regarded as critically ill or near death solely because of this technology dependence. Indeed this worry may cause individuals to avoid necessary treatment because of a fear of the misconception in health professionals' minds that technology dependence automatically suggests end of life care be considered. Janz warns that such a pessimism based "rush to judgment" should be avoided if people with disabilities are to receive optimal quality acute care.

Brindley's paper (republished from *Journal of Palliative Care*) describes his painful experience with end of life palliative care for his dying mother. As a son and ICU physician he describes being caught between trying to comply with what he had been taught in medical school and trying to honour his dying mother's wishes. His story of how his mother's clearly expressed wishes were not supported and how he even feared watching her choke to death, despite compassionate and dedicated palliative care staff, is harrowing. His position in favour of assisted suicide is controversial but his plea for open debate for its consideration in rare cases is well supported by both professional argument and his personal experience. ■

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Why is there Concern about Organ Donation after Cardiac Death?

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Recently, a group of pediatric intensive care physicians, including myself, called for a moratorium on the practice of organ donation after cardiocirculatory death (DCD) until truly informed consent could be obtained (Carcillo, et al., 2010). To some, this seemed an over-reaction to DCD clinical practice. After all, organ donation *after death* has the potential to save thousands of lives each year. The availability of organs donated after death is clearly inadequate to provide a sufficient number of organs to patients who need them, and many die on waiting lists without ever having been offered an organ transplant. Family members sometimes ask about organ donation at the end of life, with a desire to donate their own, or their loved one's organs after death. Surely DCD can offer some of these families and patients the opportunity for a life altering organ transplant. So what is the problem?

The clinical practice of DCD is as follows. First, a decision is made with the patient and/or family to withdraw life support, as the time has come to allow the patient to die. Second, once that decision is made, organ donation after death can be discussed, and with consent, can be facilitated. Third, the patient is taken to the operating room, and full life support, including the ventilator and medications, are withdrawn. At a certain time after life support withdrawal, medications are often given, to reduce the chance of damage to the organs. Catheters may be placed in the blood vessels (femoral) before life support withdrawal to allow IV infusion of organ preservative solutions once death is pronounced. After withdrawal of life support, if the patient has loss of circulation within 60 minutes, they can be an organ donor (if it takes longer, they are sent back to the intensive care unit for palliative care). Fourth, after loss of circulation for 2–10 minutes (the



time varies by institution, and is most commonly 5 minutes), the patient is pronounced dead. At this point organs are obtained by immediate surgery before excessive damage occurs.

Two main concerns with this process are the focus of my discussion. First, I contend that the patient is *not yet dead* when organ retrieval begins, and therefore DCD violates the *dead donor rule*. Second, conflicts of interest in the entire process are not avoidable and must be acknowledged. How can these concerns be supported when several medical society consensus statements (Bernat, et al., 2006; Shemie, et al., 2006) have claimed the opposite?

Death is the state of the body when it is irreversibly dis-integrated, no longer functioning as an organism as a whole, no longer resisting entropy with homeostatic functions. Irreversible loss of circulation fulfils this concept of death. *The key here is that death is irreversible*. If someone has loss of circulation reversed, we say that they have been resuscitated; we do not say that they have been miraculously brought back from the state of death. No mortal returns from the state of death, but they do return from the process of dying. With DCD there has been a prior plan made not to attempt to reverse the process of dying; when circulation is lost, a decision has been made to allow the patient to die without attempts at resuscitation. Therefore, proponents of DCD consider this loss of circulation to be permanent; and, permanent is in turn a surrogate or proxy for irreversible loss of circulation. The problem with this argument is that it takes the surrogate/proxy (prognosis) of death to be the same as the actual state (diagnosis) of death. In other words, if a condition is never actually reversed it is permanent, but if a condition never could be reversed it is irreversible (irreversibility entails permanence; permanence does not entail irreversibility, Marquis, 2010). As Marquis has written:

Suppose that Joe has a heart attack and his circulatory function stops. Fred, a physician standing next to Joe, refuses to perform

CPR on Joe because Joe is a rival... Suppose that CPR would have been successful, but because it was not performed, cessation of Joe's circulatory function was permanent. Was Fred's refusal to act wrong? Not if we understand the irreversible cessation of circulatory function as equivalent to the permanent cessation of circulatory function... On that understanding, Joe was dead as soon as he collapsed, and Fred's failure to perform resuscitation was not wrong, for he had no obligation to resuscitate a corpse.

Another example to make the point is given by Marquis:

An individual is in a severe automobile accident and arrives in the ER. You are the ER physician. You judge that the patient's blood loss is so great that the patient will soon die unless she receives a blood transfusion. Her surrogates decline the transfusion because she is a Jehovah's Witness. You respect the refusal and she dies. You would say, of course: 'Her condition was reversible! I wish I could have transfused her!' ...you would be wrong to say that... since reversing the patient's condition was not legally or morally permissible, the patient should have been viewed as being in an irreversible condition...

Proponents of DCD seem to recognize this problem and claim that, although the patient is not "ontologically" dead, by accepted medical standards they are dead (Bernat, 2006, 2010a, 2010b, 2010c; Bernat & Capron, 2010). Of course, medical standards are accepted because they accord with the way things are in the world, and therefore the argument fails. To complicate matters, this may not be only a philosophical concern about whether the patient is in the irreversible state of death. There are unusual cases (called the "Lazarus phenomenon") of patients who have been pronounced dead after failed resuscitation attempts, who have recovered

circulation on their own several minutes later (up to 10 minutes later during constant observation of the patient, Joffe, 2007). In those not having had attempts at resuscitation, for how long after loss of circulation this “autoresuscitation” can occur is unknown.

The second concern is conflict of interest. It is said that the decision to withdraw life support will be independent of the request and decision regarding DCD. However, the physician discussing withdrawal of life support will be aware of the future option of DCD and will not be able to prevent this from influencing his/her opinion. Knowledge and experience of the great benefit to patients with organ failures from organ transplantation, of several patients in the hospital now or recently with these organ failures who are desperately awaiting the gift of an organ, and of the academic and financial prestige to the institution and colleagues from organ transplantation activities are not avoidable. The psychology of decision making is complex, but it is clear that bias need not be consciously intentional, and that unconscious biases are more potent and pervasive. In addition, disclosure of conflicts of interest, while morally required, do not improve the situation, and have been shown to worsen the influence of bias on decisions. The concern that DCD will unduly bias the subjective decisions about withdrawal of life support and alter outcome is real, given that physician prognostic estimates are variable, often inaccurate, and powerfully predict withdrawal of life support and mortality (Rocker, et al., 2004; Cook, et al., 2003).

To rid the process of conflicts of interest, proponents of DCD claim that those involved in transplantation will not be the ones who discuss DCD and obtain consent from the patient/surrogate. This is at best misleading. The physicians and nurses caring for terminally ill intensive care patients, discussing withdrawal of life support, and discussing DCD, are the same ones who care for critically ill potential organ recipients and critically ill postoperative

transplanted patients. Whether they care for the exact recipient of their most recent patient’s donated organ is irrelevant. They care for both groups of patients and this creates an unavoidable conflict of interest.

These are the main reasons we called for a moratorium on DCD until these issues are openly discussed and truly informed consent is obtained. The only argument for maintaining the status quo would be to point out the good consequences that result, including saving lives by organ transplantation and maintaining trust in the medical/transplantation systems. However, consequentialist calculations in defining death are irrelevant given that our concern is the actual state (death) of the patient. We seek to diagnose the univocal state of death, regardless of the consequences. As Nair-Collins (2010) has pointed out, “biological reality [biological death] is what it is, whether we like it or not...What the argument [from utility] advocates, however, is for the medical community to intentionally deceive the public about the biological reality of death.” Similarly, others point out that the most good/bad consequences can do “is give us a reason for keeping quiet about (or exaggerating) the real status of the condition. The bad consequences cannot stop a condition from being a disorder...it is not clear that that would justify anything other than a piece of large scale public dishonesty.” (Garrard & Wilkinson, 2005)

I believe that truthful, complete, voluntary informed consent to organ donation is required. This best respects patient autonomy. Until the concerns described are seriously considered, full public disclosure occurs, and truly informed consent is obtained from donors, my colleagues and I stand by the call for a moratorium on the practice of DCD (Carcillo, et al., 2010). ■

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Social Vulnerability: An "Added" End-of-Life Issue Affecting People with Disabilities

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It is a basic fact that essentially all human beings experience a sense of, often increasing, vulnerability as they approach the end of their lives. This sense of vulnerability is most often connected with the progressive loss of function and the concurrent increased dependence on others to meet one's basic needs that generally occurs during the final stages of a person's life. This experience is almost

universal among the elderly as their previous sense of independence diminishes. For people with disabilities, however, the vulnerability experienced at the end of their lives is not a new individualistic phenomenon. It is rather an unsettling – and often literally *dangerous* – escalation of the social vulnerability that they have experienced throughout their lives. Psychologist and Disability Studies



scholar, Carol Gill, explains this heightened social vulnerability that people with disabilities often face at the end of their lives in the following terms:

Unfortunately, many people with disabilities feel particularly vulnerable in medical settings. Medical classification, emphasizing abnormality and deficiency, permeates the public's understanding of life with disability. Doctors and other healthcare professionals have served as the primary authorities in public policy affecting us, as well as in our personal life histories. Whether we remember them as kindly paternal or frighteningly austere, medical experts have diagnosed our problems, predicted our potential, and prescribed measures to alter our bodies and our futures. This is a lot of power.

... In an atmosphere where words like “extraordinary” and even “futile” get attached to supports we use each day [e.g. feeding-tubes and ventilators], we feel caught

between the power of the medical expert to decide what we need, and the power of the healthcare funding system to judge our needs as excessive. ... In this context, disabled people's distrust of the healthcare system has only intensified, impelling them toward hard decisions. Several years ago, I talked with a disabled man who has an important job, many friends, and an impressive list of accomplishments. He told me emphatically that he would never again enter a hospital no matter how critically ill he becomes. I hardly knew how to interpret such a declaration. I found it drastic and disturbing. I wondered if he was severely depressed. Before long, however, I heard other disabled persons take up this theme. Most are individuals commonly described as “severely” disabled. They appear and function in ways judged extraordinary. Some use ventilators and most require technological and human

assistance to accomplish the tasks of daily living. *In the context of their extensive physical impairments, some observers might read their avoidance of hospitalization as a rational advance directive. But that would be a misinterpretation. Rather than forego life support, they have resolved to protect themselves by bunkering themselves down in familiar surroundings until the end. The medical system, they say, is a dangerous place for them.* (Gill, 2006, p. 183-184)

I have quoted from Gill at length here because I think she both clearly articulates and compellingly illustrates the essence of the social vulnerability that many people with disabilities experience as an “added” end-of-life issue. Within the medical community, and, I would argue, particularly within the conventional health ethics community, there has been, and continues to be, an almost inherent tendency to adopt an essentialist, utilitarian approach to defining concepts of “extraordinary,” “heroic,” and “futile” measures which may be employed to preserve or prolong human life. The danger that this poses for people with disabilities, as Gill explains, is that things which are considered routine parts of daily living within the disability community, such as the use of feeding-tubes and respirators, are suddenly transformed into indicators of an unacceptably low quality of life, if not the total negation of one’s status as a truly viable human being. For this reason, it is apparent that a paradigm shift needs to take place within traditional medical care and health ethics discourse if it is to become a safe space for people with disabilities to enter, participate in, and feel that their views receive an open hearing.

But if a paradigm shift is indeed needed within traditional medicine and health ethics in order to make it safe for people with disabilities to enter and inhabit these realms, questions automatically arise as to exactly what this paradigm shift should look like and who the agents of this change should

be. Given that the process of “pathologization” of disability and those who have disabling conditions is historically and systemically ingrained in medicine and health ethics, it seems that this process can only be replaced by a more holistic view of and approach to disability through the purposeful and systematic introduction of a disability-ethics perspective into these fields.

The distinctiveness of a disability-ethics perspective centers around its focus on incorporating the perspectives of people with disabilities into ethical discussions and debates, and also connecting with the broader fields of disability studies and the traditional disciplines of philosophy and health ethics. Hence, while traditional health ethics examines “quality of life” in relation to disability in terms of the effects of an impairment on an individual’s relationship to the environment, a disability-ethics perspective requires us to also examine the effects of social



marginalization on the individual, and the effects of stigma on the societal and professional perception of the individual's quality of life. A disability-ethics perspective is thus particularly applicable in efforts to understand and address the social vulnerability that many people with disabilities experience as an "added" end-of-life issue.

The question of precisely *how* best to go about seeking to introduce and incorporate a disability-ethics perspective and approach into the established healthcare and health ethics fields is difficult and complex. However, it seems to me that the best potential for moving forward in this endeavour lays in finding ways to expose students in Medicine and Health Ethics (as well as other health-related fields) to a disability-ethics perspective as an integral part of both their pre-clinical and clinical education. While the obstacles and barriers to this kind of

transformative endeavour are significant, given that the curricula in these disciplines are generally set and often have little or no room for the addition of "extra" subject matter, it would be in keeping with the recognised need for more humanistic education of health care professionals. Indeed, many people with disabilities would strongly contend that, unless healthcare professionals begin to incorporate a disability-ethics perspective into both their training and their practice, the broad clinical realm will remain a dangerous place for people with disabilities, even and especially as they approach the end of their lives. ■

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"Good Grief": What Is a Son — and a Doctor — to Do?

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My wonderful mother died of dementia February 2 (Groundhog Day), 2005. She was a remarkable person, but also a palliative-care counsellor and a sought-after speaker on the topic (1). This was undoubtedly because of her profound humanity and understanding of end-of-life care. I therefore knew clearly what she would have wanted, and how far this was from what she received. I vividly remember the conversations that we had: she as a counsellor, me as a critical care physician. This article is about how a son, and his profession, could have done much better for "one-of-their-own". It is about how patients deserve more, just as she deserved more.

Before she deteriorated we frequently talked about the need to fight for our patients: to always battle for cures when possible, but to honour patients' wishes and ensure their dignity always. I remember her saying how secure she felt because I could defend her wishes. There are few weeks when I don't think about her. Equally, like the otherwise forgettable movie, there is no Groundhog Day (2) when I do not relive how she became mute, immobile, incontinent, frequently scared, and bereft of dignity; and how powerless I was to do anything about it.

Our family marshalled the best help available. We also kept her at home and accessed resources sadly

unavailable to others. Mercifully she died within 18 months. However, in addition to losing the love of his life, my father, through his dedication, also risked losing the other anchor in his life: his career. I can only imagine how it is for those without our advantages or those stuck in this nightmare year after year. Losing a loved one can seem unimaginable, but time can temper even that. However, years on, I am no closer to accepting why my mother had little option but to face her inevitable death without more attention to her dignity or respect for her wishes.

The medical profession's preoccupation with high-tech intervention at the expense of palliative care cannot be fully excused, but it can be largely explained. Our "dis-ease" with end-of-life issues has been well documented and continues to be inadequately addressed during training (3, 4). Furthermore, practitioners may worry that any viewpoint other than an outright rejection of death will be seen as "giving up", or even as potentially libellous support for indiscriminate euthanasia (5). Of course, this is facile. However, it is understandable in a profession that dare not lose the trust of the public, and where end-of-life conflict is common (6).

Like most physicians, and especially as a critical care practitioner, I feel pressure to keep my opinions private. However, just as most of us would fight vigorously against indiscriminate assisted suicide, most people find it simplistic that it must be inappropriate under all circumstances (7). This is inconsistent with our approach to other illnesses; we are never that absolute. In fact, the only absolutes of my medical training were "to do everything to fight reversible disease", but also "alleviate suffering" and "never prolong inevitable death". We are also expected to do what is right for each individual and to fight for a meaningful existence, not just keep people alive because we can. Nobody would have permitted my mother's admission to an intensive care unit for these reasons. Equally, few would object to strict palliation if her noncerebral organs were

irrevocably destroyed. However, my mother had the "bad luck" that her brain failed. She also had the misfortune of being human. Beloved animals are spared a similar fate.

Detractors will argue that symptom control can be achieved with tranquilizers and pain-killers. However, to suggest agitated delirium or dementia are simple to treat is naïve (8). In addition, pain control became a constant battle, a source of intense distress that high jacked our grieving process. Firstly, inadequate doses were ordered and then home-care personnel were not permitted to administer them, all with the nonsensical and never-elaborated-upon rationale of "well, what if something bad were to happen". Later, when she began to aspirate, I was forced to contemplate what I would do if she began to choke to death in front of me. The people involved were compassionate and dedicated, but they could only do the best allowed by the current system. We could certainly avoid initiating therapy, however her physical health meant months of vegetative existence. Everyone involved agreed her death would be merciful. As a result, I cannot see what was gained except months of undignified pain that destroyed our memories and mocked her wishes.



This experience certainly argues for increased palliative-care resources. However, if physicians truly are patient advocates, then we should accept that debate is equally overdue for those very rare cases where a merciful death could be considered. For example, with assisted suicide, safeguards can and must be built in to prevent abuse (9). We could demand not merely pre-directives, but multiple healthcare opinions, multiple opinions from those who knew the patient intimately, definitive tissue diagnoses, and legal opinions. In short, assisted suicide could be carefully regulated so as to be exceptionally rare. Evidence from the Netherlands shows most requests are not granted and that, over time, it has not involved less severe illnesses or less careful decision making (9). Instead, to remain silent simply propagates the current farce, where increasing numbers will demand indiscriminate euthanasia and others will become criminals (10). The parallel with abortion's past should be obvious. Our profession faced that divisive debate. We need to be courageous again.

My experiences as a doctor mean that I do not fear death. However, my experiences as a son mean that I certainly do fear death without dignity. Regardless, being a good son, just like being a good doctor, is about facing tough issues with bravery and compassion. It is also what my mother would expect of me. All I ask is that we not be afraid simply to discuss difficult topics. If not for my lovely Mum, then I'll ask you to imagine what you would want if faced with your own "Groundhog Day". It certainly forced this son and doctor to do so. ■

* Dr Peter Brindley would be happy to provide a free copy of his mother's book to any correspondent. He can be reached by e-mail at: brindley@shaw.ca

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