CONSENT AND CONFLICT IN MEDICO-LEGAL DECISION-MAKING AT THE END OF LIFE: A CRITICAL ISSUE IN THE CANADIAN CONTEXT

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INTRODUCTION

New technologies are, in many ways, making life more efficient and more productive. Ironically, these same technologies are making life more complex and precarious. In particular, medical technologies—*in vitro* fertilization, transplantation, stem-cell therapies, advanced life-support techniques—are proving to be a double-edged sword by increasing treatment options and expectations while simultaneously exciting ethical concerns about how they affect our humanity and personhood. Additionally, and importantly for this paper, we now face the ambiguous circumstance where advances in medical technology have extended our life-preserving capability (that is, our ability to maintain a functioning body), but have failed to increase, to the same extent, our healing capability (that is, our ability to restore functionality or cure the underlying debilitating condition).

Patients, families, treating physicians, and lawyers are increasingly presented with complex issues and difficult decisions that tangle healthcare desires, legal rights and duties, and ethical values. Physicians, troubled when competent patients refuse treatment deemed vital (a well-entrenched right[1]), are doubly challenged when confronted with incompetent patients represented by substitute decision-makers

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[1] In Canada, see *A.C. v. Manitoba (Director of Child and Family Services)*, 2009 SCC 30, *Rodriguez v. British Columbia (A.G.)*, [1993] 3 S.C.R. 519, and others. In the United Kingdom, see *Re T (adult: refusal of treatment)*, [1992] 4 All E.R. 649 (C.A.).

(SDMs) demanding treatment deemed "medically futile."[2] Inevitably, when the way is unclear and the parties disagree as to the right course of action, the law must intercede. At the risk of insinuating lawyers into every aspect of life (and death), it seems obvious that the legal profession has an important role to play at the endgame of life.

Although few people adequately discuss their end-of-life desires, and fewer still execute advance directives (ADs), intractable disputes over withholding or withdrawing life support are relatively rare.[3] However, given the increasing longevity and advancing age of populations and the ongoing life-sustaining/cognition-restoring deficit, such disputes will become more prevalent with the result that lawyers will more frequently be called upon to represent families or health authorities when treatment disputes arise. Given that these disputes are a source of tremendous distress for all involved,[4] as tragically demonstrated by the nine-year legal battle for control over Terri Schiavo's future,[5] lawyers have an obligation—to medical and judicial institutions, to clients and their families, and to themselves—to understand the legal and ethical issues implicated.

Given the above, this paper explores the current legal state in Canada of three core aspects of managing end-of-life situations, with reference to the United Kingdom (U.K.) where appropriate.[6] First, it briefly considers the consent model that has developed in Western medical practice, focusing on its capacity element, which is particularly significant in end-of-life settings. Second, it explores the position of

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[2] Medical futility exists when a treatment is contra-indicated by a physician's clinical judgment because it merely preserves a state of permanent unconsciousness or total dependence on intensive medical care with little or no chance of improving the patient's underlying or overall condition: L. Schneiderman *et al.*, "Medical Futility: Its Meaning and Ethical Implications" (1990) 112 Ann. Intern. Med. 949-954; M. Zucker & H. Zucker, *Medical Futility: And the Evaluation of Life-Sustaining Interventions*, (Cambridge: CUP, 1997); and K. Mason & G. Laurie, *Mason & McCall-Smith's Law and Medical Ethics*, 7th ed. (Oxford: OUP, 2006), c. 16.

[3] C. Weijer *et al.*, "Bioethics for Clinicians: Dealing with Demands for Inappropriate Treatment" (1998) 159 C.M.A.J. 817-821.

[4] M. Solomon, "How Physicians Talk About Futility: Making Words Mean Too Many Things" (1993) 21 J. Clin. Ethics 231-237, and A. Simmonds, "Decision-Making by Default: Experiences of Physicians and Nurses with Dying Patients in Intensive Care" (1996) 12 Hum. Health Care Int. 168-172.

[5] This was a divisive family saga that exploded into a titanic public moral and political mêlée, and re-opened the abortion and stem cell research debates in the United States of America: see *Re Guardianship of Schiavo* (2001), 780 So. 2D. 176 (Fla. App., 2nd Dist.). For more, see G. Pradella, "Substituting a Judgment of Best Interests: Dignity and the Application of Objective Principles to PVS Cases in the UK" (2005) 12 Euro. J. Health Law 335-345.

[6] The U.K. is a useful touchstone because of its robust jurisprudence: the High Court, Family Division, which has inherent jurisdiction in England and Wales to make declarations with respect to patients lacking competence, disposes of, on average, 20 cases per year with respect to adults alone: see *Re F (adult: court's jurisdiction)*, [2000] 2 F.L.R. 512 (H.C. Fam.).

ADs, which extend consent powers beyond the loss of capacity (and death). Third, it explores the operation of "best interests" assessments, an essential concept for shaping end-of-life decisions when the patient lacks capacity and has no applicable AD. In the course of exposing and critiquing these concepts, it highlights the ethical values that back them.[7]

The analysis is structured around the following statutes: the Alberta *Personal Directives Act*,[8] the Manitoba *Health Care Directives Act*,[9] and the Ontario *Health Care Consent Act*[10] and *Substitute Decisions Act*[11] (which combine to govern this area). These constitute a reasonable sample of Canadian jurisdictions and might together be considered representative of Canadian practices.[12] Four recent end-of-life cases emanating from these jurisdictions will also be considered: *Scardoni v. Hawryluck,*[13] *Re Grover,*[14] *Jin (next friend of) v. Calgary Health Region,*[15] and *Golubchuk v. Salvation Army Grace.*[16] The paper concludes by offering some practical suggestions for medical law practitioners giving advice in these highly emotive situations.

CONSENT OF THE (AILING) PATIENT: CAPACITY TO CONSENT

Medical law, like medicine itself, is concerned with human flourishing as well as personal integrity. Paternalism has gradually given way, hastened by medical research abuses in the last century, and a more patient-centred approach now prevails. Medical law now uniformly imposes on clinicians the "consent model," which demands that patients be empowered to make, or participate in, treatment decisions. Under this model, individuals must consent before any treatment (any physical touching) can

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[7] "Values" are the ideals that we, as individuals and as a society, hold and which move us to respond (either positively or negatively) to possibilities and responsibilities. For more on values, see A. Bruce & J. Tait, "Interests, Values and Biotechnological Risk" (2003) InnoGen WP-7, at www.innogen.ed.ac.uk, and S. Harmon, "Regulation of Human Genomics and Genetic Biotechnology: Risks, Values and Analytical Criteria" (2005), InnoGenWP-40, at <www.innogen.ac.uk/Publications/40Regulation_of_Human_Genomics_and_Genetic_-Biotechnology>.

[8] R.S.A. 2000, c. P-6.

[9] C.C.S.M. 1993, c. H-27.

[10] S.O. 1996, c. 2.

[11] S.O. 1992, c. 30.

[12] Most provinces have legislation governing ADs and the appointment of SDMs. See British Columbia: *Health Care (Consent) and Care Facility (Admission) Act*, R.S.B.C. 1996, c. 48, and *Adult Guardianship Act*, R.S.B.C. 1996, c. 383; Newfoundland: *Advanced Health Care Directives Act*, S.N. 1995, c. A-4.1; Nova Scotia: *Medical Consent Act*, R.S.N.S. 1989, c. 279; Prince Edward Island: *Consent to Treatment and Health Care Directives Act*, S.P.E.I. 1996, c. 10; Quebec: Arts. 10-25 *Quebec Civil Code*; Saskatchewan: *Health Care Directives and Substitute Health Care Decision Makers Act*, S.S. 1997, c. H-0.001

[13] (2004), 69 O.R. (3d) 700 (S.C.).

[14] [2009] CanLII 16577 (Ont. S.C.).

[15] [2008] 2 W.W.R. 273 (Alt. Q.B.).

[16] [2008] 8 W.W.R. 299 (Man. Q.B.).

occur. In *Starson v. Swayze,* an important Canadian case, the Supreme Court of Canada articulated the principle as follows:

> Ordinarily at law, the value of autonomy prevails over the value of effective medical treatment. No matter how ill a person, no matter how likely deterioration or death, it is for that person ... to decide whether to accept a proposed medical treatment.[17]

Thus, consent must be sought and patients can refuse to consent, even when the inevitable consequence is death.[18] The consequences of unauthorised touching can be a finding of assault or battery (and civil or criminal liability).

Conversely, as noted in *R. (on the application of Burke) v. General Medical Council,*[19] where patients with capacity wish to be kept alive by ventilation or artificial nutrition and hydration, there can be no question about the provision of same. There can be no clinical indication to the contrary unless a decision has been taken that the life should come to an end, and that is not a decision that can lawfully be taken for competent patients who express the wish to remain alive. It should, however, be noted that, while the consent model allows individuals to demand medical assistance, they may not necessarily demand a specific treatment (which may not be clinically indicated or available).[20] Accordingly, while individual decision-making, with its myriad non-medical motivators, has risen to great prominence, medical judgment is still important. This is nowhere more readily demonstrated than in end-of-life settings.

The consent model, with its capacity prerequisite, protects self-determination and bodily integrity and is therefore founded on two core ethical values: human dignity and autonomy. Dignity encompasses the idea that human beings, individually and collectively, are unique, deserving of honour and respect as amongst one another, and should be elevated above non-human species.[21] It contributes to our shared sense of being and our sense of inherent or natural rights (that is, rights that are neither

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[17] [2003] 1 S.C.R. 722 at para. 7.

[18] *Manitoba (Director of Family & Child Services), supra,* note 1.

[19] [2005] E.W.C.A. Civ. 1003 (C.A.).

[20] There is no unfettered right to choose treatments either under the *Canadian Charter of Rights and Freedoms* or the UK *Human Rights Act 1998*: see *Auton (guardian ad litem of) v. British Columbia (A.G.)* (2004), 245 D.L.R. (4th) 1 (S.C.C.), and *R. v. Cambridge District Health Authority ex parte B (minor),* [1995] 2 All E.R. 129 (C.A.). This is also the legal position in New Zealand: see *Shortland v. Northland Health Ltd.* (1999), 50 B.M.L.R. 255 (C.A.).

[21] For more on this value, see T. Beauchamp & J. Childress, *Principles of Biomedical Ethics,* 4th ed. (Oxford: OUP, 1994), D. Beyleveld & R. Brownsword, *Human Dignity in Bioethics and Biolaw* (Oxford: OUP, 2001), and M. Cutter, "Genetic Databases and What the Rat Won't Do: What is Dignity at Law?" (217-222) and D. Statman, "Human Dignity and Technology" (223-228) both in G. Arnason *et al.* (eds.), *Blood and Data: Ethical, Legal and Social Aspects of Human Genetic Databases* (Reykjavik: U. of Iceland Press, 2004).

specifically granted nor legitimately violated by society), and it has informed the norms espoused by numerous international instruments.[22] Autonomy is grounded in respect for the worth of human beings: it encompasses physical, psychological, and legal liberty and the right to be free from controlling influences (of others and of personal limitations) with respect to same.[23] Indeed, the Ontario legislation declares the enhancement of autonomy as one of its purposes and the Supreme Court of Canada specifically considered it in *Starson*.[24] It can thus be said that dignity and autonomy have found a legal voice in the end-of-life decision-making framework. The consent model, with its insistence on capacity and its mechanisms for testing same, might even be described as the ultimate expression of these ethical values.

The Manitoba and Ontario acts specifically endorse the consent model,[25] whereas the Alberta act assumes the model without reference. All the statutes are in substantial agreement as to the conceptualization and formulation of capacity: people are entitled to make decisions when they are not labouring under mental or psychological conditions that negate their capability. As evidenced in this legislation, the cornerstone of the consent model is the individual's capacity to consent. Infirmity can be quite pronounced when end-of-life decisions are being made, so there is a particular need to ensure the capacity of patients (and to protect those lacking capacity). The common law presumes capacity (in adults) and the Manitoba and Ontario acts retain that presumption. Those challenging capacity must prove its absence on the balance of probabilities.[26] A person is deemed to have capacity when he or she is able

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[22] Charter of the United Nations, 26 June 1945, Can. T.S. 1945 No. 7, *Universal Declaration of Human Rights,* GA Res. 217 (III), UNGAOR, 3d Sess., Supp. No. 13, UN Doc. A/810 (1948), International Covenant on Economic, Social & Cultural Rights, GA Res. 2200A UN GAOR (1966), International Covenant on Civil & Political Rights (1966), African Charter on Human & Peoples' Rights (1981), Declaration on the Rights of Persons Belonging to National or Ethnic, Religious & Linguistic Minorities (1992), Declaration on the Elimination of Violence Against Women (1993), Arab Charter on Human Rights (1994), UNESCO's Universal Declaration of the Human Genome and Human Rights (1997).

[23] T. Beauchamp & J. Childress, *supra*, note 24, at 121, S. Aksoy & A. Elmali, "The Core Concepts of the 'Four Principles' of Bioethics as Found in Islamic Tradition" (2002) 21 Med. Law 211-224, and R. Gillon, "Ethics Needs Principles - Four Can Encompass the Rest - and Respect for Autonomy Should be 'First Among Equals'" (2003) 29 J.M.E. 307-312.

[24] *Supra*, note 10, s. 1(c), which also lists facilitating treatment and promoting communication as purposes, and see paras. 7 and 11, *Starson v. Swayze, supra*, note 17.

[25] *Supra*, note 9, preamble, and *supra*, note 10, s. 1(c). The SDA (Ont) assumes the model without specifically addressing it.

[26] *Starson v. Swayze, supra*, note 17, and *supra*, note 9, s. 3, which refers to the Manitoba *Mental Health Act*, and *supra*, note, 10, ss. 4(2) and (3). In the English context, see ss. 1(2), (3) and (4), and s. 2(4) of the *Mental Capacity Act 2005*, c. 30.

to: understand the information that is relevant to making a treatment decision and appreciate the reasonably foreseeable consequences of a decision or lack of decision.[27]

In the subject cases, capacity was not controversial—none of the patients had it. In *Scardoni*, the 81-year-old patient with advanced Alzheimer's, aspiration pneumonia, recurrent lung infections, painful bedsores, and reflection contractures, was non-responsive and unable to recognize people. In *Grover*, the previously partially disabled 81-year-old patient suffered a stroke that left her non-communicative and quadriplegic. In *Jin*, the previously healthy 66-year-old patient fell and suffered a severe head injury causing unconsciousness and was treated with brain inserts (to reduce pressure and ensure blood flow). In *Golubchuk*, the patient also suffered a closed head injury: he neither ambulated nor spoke, though there was some dispute over the level of his brain function as his treatment team was claiming non-responsiveness to stimuli. All of the patients, save Mrs. Holland, the patient in *Scardoni*, were on ventilators and required tube-feeding. None were in a position to actively participate in decisions concerning their treatment. As none of the cases addressed capacity in any detail, they contain no pertinent discussion or development of the relevant values.

ADVANCE DIRECTIVES AND THE (INCAPAX) PATIENT: FUTURE CONSENT

Patients who have lost capacity may have left instructions or outlined the scope and limits of their future consent in the form of an AD executed when they were competent. As with the consent model more generally, ADs constitute a preservation of autonomy, extending it to periods where judgment can no longer be exercised by the patient (for example, ADs may contain instructions on the use and disposition of the body). While this approach is decidedly anti-communitarian (that is, an alternate approach might limit the patient's post-morbid choices, vesting certain decisional powers with authorities responsible for public health and public health research), it is important for promoting another important value—trust. In particular, it promotes patients' trust in physicians and health authorities that they will make decisions based on the particular case and that advance their patients' welfare. This in itself can have important public and personal health consequences and so might be viewed as a reasonable concession to other public needs (for example, the need for tissue and organs).

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[27] *Supra*, note 9, s. 2, and *supra* note 10, s. 4(1), and *supra*, note 11, s. 45. Section 1(b) of the Alberta Act adopts those two criteria as the definition of capacity, and s. 3 incorporates them into the definition of a person eligible to make an AD. The English legislation adopts the same criteria, although it approaches the issue from the perspective of someone lacking capacity, stating that one lacks capacity and cannot make a decision where they lack the above capabilities: see ss. 2(1) and (2) and *Mental Capacity Act*, supra note 26, s. 3.These statutory tests are reflective of the common law as enunciated in *Re C (adult: refusal of medical treatment)*, [1994] 1 All E.R. 819 (H.C.), and *Re MB (adult: medical treatment)*, [1997] 2 F.C.R. 541 (C.A.).

ADs can be amended or withdrawn.[28] They only take effect once incapacity is proven,[29] at which point a person's most recent capacity-supported wishes prevail.[30] As a matter of common sense, an AD is not applicable if the patient retains capacity at the relevant time or the condition/treatment is not captured by the terms of the AD. The Alberta and Manitoba acts are expressly concerned with written ADs,[31] whereas the Ontario acts are more broad, stating that a person, while capable, may express future treatment wishes either through: a power of attorney for personal care in prescribed form, another written form, oral statements, or any other manner.[32]

Under these acts, the duly appointed SDM must pay close attention to the patient's wishes and conform to them with respect to giving or refusing consent whenever the circumstances specifically arise.[33] The Court of Appeal for Ontario has, however, cautioned that:

> ... prior capable wishes are not to be applied mechanically or literally without regard to relevant changes in circumstances. Even wishes expressed in categorical or absolute terms must be interpreted in light of the circumstances prevailing at the time the wish was expressed.[34]

Similarly, the English Court of Appeal,[35] considering patients who had lost capacity, held that directions in an AD are not necessarily determinative. While the law requires compliance with valid ADs, this means nothing more than taking the wish into consideration when determining the patient's best interests. This approach recognizes that treatment can prolong life indeterminately, but sometimes at the cost of terrible suffering. The Court noted a very strong presumption in favour of taking steps that prolong life, holding that the best interests of the patient usually square with this

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[28] *Supra*, note, 8, ss. 8 and 10, *supra*, note 9, s. 9, and *supra*, note, 11, ss. 47 and 53.

[29] *Supra*, note 8, s. 9, *supra*, note 9, and *supra*, note 11, ss. 49 and 51.

[30] *Supra*, note 8, s. 8, *supra*, note 9, s. 9, and *supra*, note 10, s. 5(3).

[31] Both stipulate the ADs must be written, signed, dated, and witnessed: *supra*, note 8, s. 5, *supra* note 9, s. 8. Also *Mental Capacity Act*, *supra*, note 26, ss. 24(3), (4) and (5). The English Act states that a person, when he has capacity to do so, can specify that, in the event of loss of capacity, certain treatment is not to be carried out or continued, but where the treatment in question is life-sustaining, it must be in writing: *Mental Capacity Act*, *supra* note 26, ss. 24 and 25.

[32] *Supra*, note 10, s. 5(2), and *supra*, note 11, s. 46, which erects the criteria for executing a power of attorney for personal care.

[33] *Supra*, note 10, s. 21(1)1, and *Neill v. Pellolio* (2001), 151 O.A.C. 343, and *supra*, note 26, ss. 11(7) and 26(1).

[34] *Conway v. Jacques* (2002), 159 O.A.C. 236, at para. 31. This caution is supported by M. Gordon & D. Levitt, "Acting on a Living Will: A Physician's Dilemma" (1996) 155 C.M.A.J. 893-895, and by statements in the *CMA Code of Ethics*, *supra*, note 14, to the effect that a physician is never required to carry out instructions that conflict with his/her own ethical principles.

[35] *R. (on the application of Burke)*, *supra*, note 19.

presumption. If doubt exists, life is typically preserved in keeping with the sanctity of life value. Moreover, every case on providing or continuing care will depend on its particular circumstances. Where the patient is clearly dying, the goal may properly be to ease suffering.

The legislative schemes reflect this suspicion of mechanistic approaches. The Alberta *Personal Directives Act* states that an SDM (agent) must follow any clear instructions provided in the AD that are relevant to the decision to be made; if the AD does not contain clear instructions, the SDM must make the decision he or she believes the patient would have made in the circumstances, based on the SDM's knowledge of the wishes, beliefs, and values of the patient. If these are unknown, the SDM must make the decision that he or she believes in the circumstances to be in the patient's best interests.[36]

The Manitoba *Health Care Directives Act* states that an SDM (proxy) must comply with healthcare instructions where expressed. Where they are not expressed the SDM must act in accordance with any wishes he or she knows the patient expressed when capable and believes the patient would still act on if capable, or even if that expression is contrary to instructions in the AD, if the expression was made after the execution of the AD. If the SDM has no knowledge of the patient's wishes, he or she must act in what he or she believes to be the patient's best interests.[37]

The Ontario legislation states that an SDM must give effect to the patient's known wishes; if the patient's wishes are unknown or are impossible to comply with in the particular circumstances, then the SDM must act in the patient's best interests.[38]

Relevant here are the Ontario cases of *Scardoni* and *Grover*. In both cases the patients had ADs and designated SDMs, and there was dispute between the SDMs and physicians over the appropriate course to follow. In Ontario, if the treating physician is of the opinion that the SDM failed to comply with his or her duties in making a decision, the physician can apply to the Consent and Capacity

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[36] *Supra*, note 8, s. 14. Section 15 outlines decisions the SDM is not entitled to make without express authority.

[37] *Supra*, note 9, s. 13. Section 14 outlines decisions the SDM is not entitled to make without express authority.

[38] *Supra*, note 10, s. 21(1), and *supra*, note 11, s. 66.

Board (CCB) for a determination.[39] In these cases, the physicians applied to the CCB seeking: determinations as to whether the SDMs, in taking the positions they did, were in compliance with their statutory duty to take decisions in the best interests of the patient, and orders declaring that their own proposed course was lawful.

In *Scardoni*, the physician considered intensive care unit (ICU) administered ventilator and inotropic support for respiratory failure and septic shock to be medically futile because of the burden such treatment imposed and the impossibility of reversing the advanced stage of Mrs. Holland's Alzheimer's. Thus, she sought authorization for the non-provision or withdrawal of such treatment should Mrs. Holland experience another episode necessitating it in the future. The SDM argued that, since Mrs. Holland was not in a vegetative state and not receiving ICU treatment and could in future respond favourably to such treatment (as she had in past), authorizing the physician as requested would amount to "a significant step down the slippery slope towards professionally-assisted euthanasia."[40]

In reviewing the CCB's decision permitting the physician to withdraw/ withhold care, the Court observed that the term "wellbeing" incorporates not only life itself, but considerations surrounding the quality of life (for example, contentment, prosperity, happiness, health, pain levels, and dignity) and that it has both a subjective and objective element. Subjectively, the SDM must take into account the patient's values, beliefs, and wishes (although not all are necessarily directly applicable), some of which may be inferred. Objectively, the SDM must consider the benefits and burdens of treatment, which will be driven by medical evidence and interests.

On the subjective side, the Court noted that the CCB made its decision based on medical evidence from a physician who was neither aware of, nor had inquired about the existence of an AD. Although couched in general terms, that AD was relevant to determining whether a patient's wishes are applicable to the circumstances. The Court was also critical of the CCB's disregard for the patient's religious beliefs (a deeply held Catholicism that valued the preservation and prolongation of life and had prompted her to claim, "where there's life, there's hope"). Though Mrs. Holland had

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[39] *Supra*, note 10, s. 37(1). The CCB, established under the HCCA, is an independent tribunal that adjudicates consent and capacity issues under a variety of acts with the intent of balancing the rights of the vulnerable and public safety: see http://www.ccboard.on.ca/scripts/english/aboutus/index.asp. In hearings before the CCB, the treating physician, SDM, patient, and any other person specified by the CCB are eligible participants, and the CCB can give the SDM directions or substitute its own decision: *supra*, note 10, s. 37. Under the English Act, a court is authorized to make declarations as to the lawfulness of the SDM's conduct in relation to the patient: *Medical Consent Act*, *supra* note 26, s. 15. In exercising its authority, the court can appoint a deputy to make further decisions on the patient's behalf, and both the court and that deputy must take into consideration the patient's best interests, as set out in the Act: *Medical Consent Act*, *supra* note 26, ss. 16(3) and (6) and ss. 20(5) and (6).

[40] *Supra* note 13.

only made general statements of philosophy not directed at coping with the myriad conditions of advanced Alzheimer's, those statements were relevant. On the objective side, the Court complained that the CCB failed to elicit critical evidence about: how long Mrs. Holland would survive and in what degree of pain and/or discomfort should pneumonia recur, whether Mrs. Holland had any chance of recovery should pneumonia reoccur, and what pain/discomfort Mrs. Holland might suffer.

The Court held that it is essential for the CCB to understand both the nature of the inquiry under each element of the best interest test and the medical evidence. It could not infer, on a balance of probabilities, that the Board's decision would have been the same had these errors not occurred. The Court concluded as follows:

> [99] It appears from the evidence ... that the appellants were emotionally upset and distressed at the meeting at which they declined to consent to the proposed plan of treatment and that their evidence at the hearing was far more specific with respect to their mother's beliefs, values and wishes. Mrs. Scardoni testified that they were intimidated. At the conclusion of the hearing, Dr. Hawryluck indicated that her decision to apply to the Board was influenced by the appellants' failure ... to be explicit about their mother's views. In view of the possibility that, having heard the appellants' evidence at the hearing, as well as having knowledge of Mrs. Holland's medical history since then, the physicians' opinions of Mrs. Holland's best interests may have changed, I do not intend to order a rehearing before the Board.[41]

The result was that the Court set aside the CCB's decision without prejudice to any further application the physician might feel was warranted in light of Mrs. Holland's future condition.

More recently, in *Grover* the patient executed a standard form healthcare directive naming her daughter as SDM. It expressed the wish that, in the event of illness and incapacity, physicians do everything medically and surgically possible to cure her or prolong her life, including heroic measures. After consulting the SDM on two treatment plans, one permitting the withdrawal of care and the other involving full, high risk treatment with questionable benefits, the physician recommended the former, noting that Mrs. Grover could not be kept indefinitely in the ICU. The SDM demanded the second plan and could not be dissuaded despite her siblings' views that Mrs. Grover would not wish to languish in her present condition. The physician concluded that the SDM was not acting in Mrs. Grover's best interest and applied to the CCB.

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[41] *Ibid.* at para. 99.

The CCB had to consider whether the wish for heroic measures was applicable to the circumstances and, if not, what Mrs. Grover's best interests were as between the two treatment plans. Ultimately, it ordered the SDM to consent to the withdrawal of life support; she appealed, claiming that its reasons were insufficient. After concluding that the CCB's reasons were sufficient, the Court articulated the dispute as foll

> [20] ... The important issue, in dispute ... was whether the ... Level 4 care set out in the ... directive applied to Mrs. Grover's circumstances... . A fair reading of the reasons ... makes it clear that the Board found the wish did not apply because when it was made Mrs. Grover did not take into account the nature and extent of the medical result to her from an event as devastating as her third stroke ... .[42]

On the issue of whether the CCB failed to take into account Mrs. Grover's wish for heroic measures, the SDM argued that the CCB should have sought evidence from nursing home staff to explore the details of Mrs. Grover's wishes. The Court held that the SDM, represented by counsel, could have called the physician but, in any event, held he could have added little to the text in the AD. Moreover, the CCB was aware of Mrs. Grover's wish for heroic measures. Thus, sufficient and relevant evidence existed and was weighed by the CCB. On the issue of whether Mrs. Grover's wish was relevant to the circumstances, the Court noted that the SDM's own evidence was equivocal enough that the CCB's conclusion was justified.[43] In dismissing the appeal and upholding the CCB's order that treatment could be withheld, the Court noted that this was a difficult case because the prior wish had been made so close in time to Mrs. Grover's third stroke.

These cases illustrate the ambiguity around ADs. First, they demonstrate the vital importance of having intimate knowledge of the content of ADs, making healthcare professionals aware of them and, when making decisions with respect to the patient, making healthcare professionals consider ADs carefully. Conversely, they show that even when ADs exist, they are neither absolute nor unconditional; they do not give patients an unfettered right to demand any and all treatment, but rather the ability to articulate a desire for a particular type of care (which may not, in fact, be available). These cases also demonstrate the need for a robust approach to weighing the benefits and burdens of treatment. Such an approach means making quality-of-life judgments, which are difficult, subjective, and comparative. Faced with "life

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[42] *Ibid.* at para. 20.

[43] Parts of the transcript were reproduced, including the following exchange: Q: Have you had conversations with your mother specifically about how she would want to be dealt with in circumstances such as this where she had a ... brain stem stroke? A: We didn't talk about a third stroke, but as I say, she did adapt pretty well to any disability. Q: You mentioned ... that your mother simply accepted ... the way she was; that was the prior stroke which was not nearly as devastating as the brain stem stroke, correct? A: Yes. Q: So the context in which she is mentioning these things to you ... are ... different ... . A: That's true.

(not) worth living" evaluations, competition for scarce healthcare resources, and a constellation of other factors that will vary from case to case (some more compelling than others) decision-makers may find such undertakings troubling, even unsavoury.[44] These difficulties are why good relations amongst the relevant parties are so important. In *Scardoni* and *Grover*, these relationships had broken down.

These cases are also noteworthy indicators that the jurisprudence is broadly reflective of critical ethical values. The rulings are consistent with:

- a careful interpretation and application of the value of preserving the inherent dignity of persons whose continued existence is at issue;
- a frank recognition of the special position of human life and each patient's inherent and inviolable right to life, legitimately curtailed by conditions that form exceptional circumstances;
- a full consideration of those elements that must reasonably and logically inform the exploration of an incompetent patient's best interests and erstwhile autonomy; and
- an implicit acceptance of both patients as individuals with unique value and place in the community, concomitant with a level of reverence and *gravitas* that the realisation of justice in such difficult circumstances requires.

In short, these cases suggest that the courts are sensitive to the ethical values of dignity, autonomy, sanctity of life, and justice, if not always explicitly so, and to the inherent tensions between them: that is, values are not absolute and no single value can govern decisions. Finally, they also demonstrate the vital importance of understanding the best interests' test.

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[44] J. Blackmer, "Tube Feeding in Stroke Patients: A Medical and Ethical Perspective" (2001) 28 Can. J. Neuro. Sci. 101-106. P. Suber, "Against the Sanctity of Life" (1996) at www.earlham.edu/~peters/writing/ sanctity.htm [accessed 5 August 2005], at 8, suggests that perhaps we should not permit brain-dead patients to monopolise life-saving/preserving equipment at the risk of healthier patients becoming acute without them. It should be noted, however, that where health authorities recommend withholding or withdrawing treatment, they are careful to point out that such distributive justice evaluations have played no role.

BEST INTERESTS OF THE (INCAPAX) PATIENT: WHO CONSENTS?

The final key aspect to end-of-life decision-making is the concept of best interests. If the AD does not expressly address the prevailing situation or if it is impossible for the SDM to comply with the wishes as understood, then the SDM must act in what he or she believes to be the patient's best interests. Similarly, in the absence of an AD, the SDM (whether a family member, physician, or public authority) must make decisions based on the patient's best interests. How is this term identified or defined?

First and foremost, it is about the paramountcy of patient welfare. In *Re J (minor)(wardship: medical treatment)*,[45] Lord Donaldson MR stated that calculating best interests cannot be done with any mathematical precision:

> There is a very strong presumption in favour of a course of action which will prolong life, but ... it is not irrebuttable. ... [A]ccount has to be taken of the pain and suffering and quality of life which the [patient] will experience if life is prolonged. Account also has to be taken of the pain and suffering involved in the proposed treatment itself.[46]

After affirming the instinct for survival and reiterating the sanctity of life, he noted that the SDM must look at the situation from the point of view of the patient and give effect to (or allow for) the fact that many people find an acceptable, if not reasonable, quality of life in situations that others might find intolerable.[47] In *Re L (medical treatment: benefit)*,[48] Dame Butler-Sloss added that the strong presumption in favour of preserving life is diminished where treatment is futile; the broadest subjective, objective, ethical, and legal considerations notwithstanding, there is no obligation on the medical profession to provide medically futile treatment.[49] This fact is the kernel of many disputes, including those in *Scardoni* and *Grover* above, and *Jin* and *Golubchuk* below.

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[45] [1990] 3 All E.R. 930 (C.A.).

[46] *Ibid.* at 938.

[47] See also *Airedale NHS Trust v. Bland*, [1993] 1 All E.R. 821 (H.L.), wherein the Lords agreed that best interests must be given a generous interpretation that encompasses medical, emotional and other welfare issues, and which emphasizes the sanctity of life. In the mental health setting, best interests has been held to include social considerations: see *R. v. Bournewood Mental Health Trust ex parte L*, [1999] A.C. 458 (H.L.).

[48] [2005] 1 F.L.R. 491 (H.C. Fam.)

[49] This latter claim is equally applicable in Canada: see CMA, "Joint Statement on Resuscitative Interventions" (1995) 153 C.M.A.J. 1652A-C, Senate Committee on Euthanasia & Assisted Suicide, *Of Life and Death* (Ottawa: Supply & Service Canada, 1995), and *Child & Family Services of Central Manitoba v. Lavallee et al.* (1997), 154 D.L.R. (4th) 409 (Man. C.A.).

A similar approach prevails in Canada, where both *E. (Mrs.) v. Eve*[50] and *Norberg v. Wynrib*[51] make it clear that determining the best interests of another requires information, deliberation, and integrity. It is complicated where, as is often the case, one of the relevant parties has personal interests that might bias the assessment. Of the three legislative schemes, only the Ontario legislation facilitates the best interests assessment through the enumeration of relevant criteria:[52]

- the patient's known values and beliefs;
- the patient's express wishes for treatment (which are non-binding);
- whether the treatment is likely to: improve the patient's condition or wellbeing, prevent the patient's condition or wellbeing from deteriorating, or reduce the extent or rate which the patient's condition/wellbeing is likely to deteriorate;
- whether the patient's condition/wellbeing is likely to improve, hold, or deteriorate without treatment;
- whether the expected benefit to the patient outweighs the risk of harm; and
- whether a less restrictive/intrusive treatment would be as beneficial as that proposed.

The Ontario legislation also recognises the depth of the assessment these criteria impose and therefore entitles the SDM to information such as the nature of the

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[50] [1986] 2 S.C.R. 388.

[51] [1992] 2 S.C.R. 226.

[52] *Supra*, note, 10, s. 21(2). *Supra*, note 11, s. 66. Under the *Mental Capacity Act*, *supra*, note 26, s. 4, the patient's best interests are determined by considering "all the relevant circumstances", including whether the patient is likely regain capacity with respect to the matter in question and when that might be; (b) the patient's beliefs and values that would likely influence a capacity-supported decision by the patient; (c) the patient's past and present wishes and feelings; (d) other factors that the patient would likely consider; (e) the opinions of anyone named by the patient as someone to be consulted on the matter in question; (f) the opinions of those with responsibility for the patient's welfare (for example, care-givers); (g) the opinions of donees of "lasting power of attorney" or court-appointed deputies. The SDM is *not* entitled to base the decision on the patient's age, appearance, condition, or aspects of behaviour that might lead to unjustified assumptions about best interests, nor can he or she be motivated (where life-sustaining treatment is concerned) by a desire to bring about the patient's death.

proposed and alternative treatments, the expected benefits, material risks, and including side effects of the proposed and alternative treatments, and the likely consequences of no treatment at all.[53]

In *Jin* and *Golubchuk*, the remaining subject cases, neither patient had executed an AD and decision-making had devolved to their children and physicians upon incapacity. These parties disagreed as to the appropriate course. In short, like the previous cases, there was a dispute over what constituted the patients' best interests but, uniquely, the disputes stemmed from the imposition by the physicians of do-not-resuscitate (DNR) orders on the patients' charts without consulting or getting consent from the families. As both judgments are on the limited question of the propriety of granting or continuing an interim injunction, neither completely dispose of the question.

In *Jin*, the patient's daughter sought an emergency interim injunction enjoining the hospital from exercising a DNR order that was imposed simply by virtue of her father's patient classification pending the decision of the hospital ethics committee. The DNR order had been issued by the ICU physicians as a result of their opinion, after six CAT scans and a worsening of Mr. Jin's condition, that Mr. Jin had entered a persistent vegetative state and would likely succumb to his head injury. Mr. Jin's daughter believed her father's condition was not so hopeless and further argued that her brother should be permitted to travel to Canada before Mr. Jin died. On the basis of the narrow scope of the application, the Court had to determine: whether a serious issue existed, whether there would be irreparable harm absent an order, and whether the balance of convenience favoured the granting of the remedy.

On the first question, the Court articulated the issue as follows: who decides about a DNR order when the patient cannot, and the family and physicians disagree? It noted an absence of Alberta authority and the possible constitutional implications, and concluded that there existed a complex legal issue demanding a full hearing involving all relevant parties canvassing all relevant considerations. On the second question, the Court accepted that there was a clear possibility of irreparable harm to Mr. Jin if the DNR order was not lifted; while he may not require or survive resuscitation, damages

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[53] *Supra*, note 10, s. 22(1). Although the English Act does not articulate specific medical information to which the SDM is entitled (from physicians or others), the direction that he or she consider "other factors that the patient would likely consider" implies the facilitation of requests from an SDM for information regarding treatment benefits, burdens, intrusiveness, risks and alternatives including non-treatment. This position is bolstered by the *Medical Consent Act*, *supra* note 26, s. 36(2), which entitles the authority to make regulations relating to mental capacity advocates, which include requiring the advocate to obtain relevant information, ascertain alternative courses of action for the patient, and further medical opinions.

would be inadequate if he were permitted to die. On the balance-of-convenience question, the Court held that granting the injunction was supported:

> [40] ... While an injunction is an extraordinary remedy, this is an extraordinary situation. I take into account the crucial nature of this decision; the importance of informed decision-making; the family's stated need for more time to understand and assess the medical information ... ; the real risk of cardiac arrest at any moment ... ; that Mr. Jin [had been] healthy ... ; and the fall occurred just over a week ago. The impact of the son wanting to attend upon his father is a less weighty consideration. ... On the other hand, the medical practitioners are said to agree that a DNR order is warranted; an injunction may require physicians to practice in ways they believe are not in their patient's best interests; and even though it was not argued by anyone I have taken into account that medical services are resources to be allocated. I am mindful that the injunction is for a brief period and on balance I prefer to rescind the DNR order, and preserve the *status quo* until there is either consensus or a legal determination on full evidence.[54]

In the result, a 24-hour injunction was granted. It used the wording and classifications used by the hospital so as to be readily comprehensible to front-line workers and was accompanied by an order that the hospital share information with the family.[55]

In *Golubchuk*, after fashioning a treatment plan with the hospital ethics committee, the treating physician informed the family that he intended to remove Mr. Golubchuk from life support. The family, acting through Mr. Golubchuk's son, obtained an emergency interim injunction restraining him. The defendant's evidence was that Mr. Golubchuk had a complete loss of consciousness, rarely opened his eyes, was unresponsive to stimuli, and unable to follow simple commands. The family produced an affidavit of a neurologist who, upon reviewing the hospital record, noted the absence of neurology examinations, CAT scans, or MRIs, and of assessments for treatable neurological illnesses that might account for his apparent lack of consciousness. The evidence also indicated that discontinuing life-support would involve some interaction with Mr. Golubchuk's body (that is, the necessary provision of narcotics) and would lead to his passing sooner than if he remained on the ventilator.

The Court opined that in cases of non-consensual medical decisions, be they to provide, withdraw, or refuse treatment, there is a role for the courts in making factual determinations and advising of the legality of disputed decisions. Given the

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[54] *Supra*, note 15 at para. 40.

[55] It is worth noting that relations between the physicians, hospital, and family remained cooperative throughout, in stark contrast to how completely relations broke down in *Scardoni*.

issue—whether an injunction should be continued until trial—the Court articulated its role as deciding whether it was just or convenient to do so.

The Court reviewed two judgments concerning withdrawal of treatment absent consent. The first, *Manitoba (Child & Family Services) v. R.L.*,[56] saw an infant admitted to hospital in a vegetative state from which there was no hope of recovery. Physicians recommended a DNR order but his parents, suspects in the precipitating attack, opposed the order. The Court noted that the placement of a DNR order involves no commission equivalent to an assault and so no consent or court order in lieu thereof is required. The second, *Sawatzky v. Riverview Health Centre Inc.*,[57] saw a 79-year-old Parkinson's sufferer with chronic aspiration pneumonia and dementia deteriorate such that physicians placed a DNR order on his chart without consulting his wife, who sought an injunction. The Court noted that *R.L.* suggested that decisions not to provide treatment are within the purview of the physician, but that case failed to consider the effect of the *Canadian Charter of Rights and Freedoms* and the Manitoba *Human Rights Code*. It therefore granted the injunction.

According to the Court, the strength of the patient's case turned on who properly has final say in the event of impasse, which often turns on whether the intervention requires a commission or an omission. On that point, it held as follows:

> [25] [It] is not settled law that, in the event of disagreement between a physician and his patient as to withdrawal of life supports, the physician has the final say. In *Sawatzky*, the court held that there was an untested triable issue relating to the applicability of the Charter ... [and even] if the Charter does not apply, common law principles must develop in keeping with Charter values, which include respect for religious freedom and respect for life and personal autonomy ... . The decision in *R.L.* ... does not resolve the issue of who has the right to decide whether to withdraw a ventilator that has been put in place. Should this issue be resolved by whether the treatment in question is an act of commission or omission? Should withholding of treatment and withdrawal of treatment be treated the same? Are there other criteria or factors to be considered? Does the plaintiff have a right to continuation of the treatment that is in place, either at common law or under the Charter? In my view, the resolution of these questions is wide open ... [and] are not frivolous.[58]

Given these conclusions, the Court decided the remaining factors as follows:

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[56] (1997), 154 D.L.R. (4th) 409 (Man. C.A.).

[57] (1998), 167 D.L.R. (4th) 359 (Man. Q.B.).

[58] *Ibid.* at para. 25.

- Sufficiency of damages: damages would not be adequate for Mr. Golubchuk because, if he died after disconnection, no judicial relief could compensate him or his family.

- Balance of convenience: continuation of the injunction could mean compelling the physicians to treat despite ethical concerns. It could also mean that Mr. Golubchuk may be afforded an opportunity to be heard fully on his positions. The balance therefore favours Mr. Golubchuk.

- Desirability of the status quo: Mr. Golubchuk is on a ventilator because the physicians placed him there; it might be assumed that, at one point, doing so squared with an ethical assessment. The status quo favours Mr. Golubchuk.

- Special circumstances: a question exists pertaining to the right that should be afforded to patients to be provided with a written outline of the procedures available and an opportunity to have any disagreement addressed with the help of knowledgeable, trained, objective mediators from outside the hospital.

In the result, it concluded that it was just and convenient to make an order continuing the injunction until a trial decision issued.

As these cases addressed the very short-term best interests of the patients rather than their ultimate best interests, they neglected to engage with the full best interests criteria enumerated above. One hopes that when the parties' rights are finally settled, the courts will indeed explore in detail these criteria and the underlying values. Additionally, these cases raise the following important questions:

- Might permitting physicians to act independently or have final say mean a return of paternalism?

- Might such an approach result in an erosion of patient autonomy and of trust?

- Might the determination of this question finally offer a frank and explicit judicial discussion of how resource allocation plays (or should play) into these decisions?

- How might the competing interests and values be balanced and how might patient rights be weighed against physician rights (as shaped by their interpretation of their ethical duties)?

That the implications of non-consultation based on opinions of futility could be far reaching is obvious.[59]

The courts in *Jin* and *Golubchuk* did not give an indication of where they stood with relation to unconsulted impositions of DNRs and did not explicitly explore any core values, though a clear affinity with the sanctity of life was evinced, the courts being concerned to preserve life—even life of questionable value from an experiential perspective—at least until final determination of the issue. Indeed, the value of sanctity of life is implicated by the best interests approach more generally. This value gives recognition to the special gift that is life. In its strictest formulation, commonly referred to as vitalism, life is inviolable and demands preservation at all costs. A milder formulation suggests that human life be treated with reverence and respect, but its preservation is linked to considerations of other life-dependent interests, needs, desires, attributes, and qualities (that is, that complex of powers and interests that we collectively call the person).[60] This non-absolute formulation assumes an aversion to harm that implicates principles such as non-maleficence and beneficence. While *Scardoni* and *Grover* seemed to adopt the milder formulation, the *Jin* and *Golubchuk* courts seemed to adopt the stricter formulation for the purpose of these applications, suggesting a judicial awareness of the differing needs in different circumstances, even from a value perspective.

The best interests approach, together with the examined cases, also serves as a means of realising a justice value—extending fairness to those in the process of dying (and to their SDMs). The particular manifestation of justice implicated here, the assurance of representation (and choice in same) and of access to a framework for conflict resolution, is administrative. From a value perspective, it encompasses fair, equitable, and appropriate treatment in light of what is owed to the individual by his or her community, including an appropriate opportunity to share in available resources through the provision of care based on medical expertise, medical need, and individual interests. The shift from patient wishes to more objective approach limits the third-

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[59] In *R. (on the application of Burke)*, *supra*, note 19, the Court accepted evidence that 50,000 patients are admitted to ICUs annually in the UK, 30% of whom die before discharge, most because treatment is withdrawn or limited (that is, clinicians conclude that such treatment would likely only prolong the process of dying). Importantly, this is done even when there is disagreement on the part of those concerned. The Court held that it is incumbent on physicians to seek legal advice, but not necessarily court approval of their conduct. It concluded that good practice may demand that physicians seek such a declaration where the legality of proposed treatment is in doubt, but they are not required to do so as a matter of law.

[60] P. Suber, *supra*, note 41, at 6-7.

party SDM's opportunity to relegate the patient's interests to a position of subservience to his or her own; it protects the patient from harm but it also permits experts to play a greater role as the patient's own faculties dim. Ultimately, then, although *Jin* and *Golubchuk* are only prologues to the resolution of a very important question, they do disclose, rather consistently, the translation of end-of-life values into practice.

CONCLUSION AND RECOMMENDATIONS FOR END-OF-LIFE PRACTICE

The scope of this paper has been fairly wide ranging: it addressed the legislative and judicial treatment of consent, capacity, best interests, and the role of ADs in Canada. Conversely, the ambition has been reasonably limited: to elucidate recent judicial holdings on practices around these important end-of-life concepts and to identify some core values implicated, thereby touching upon the underexplored area of the *interaction* between socio-ethical values and law and the *translation* of values into statutory rules and judicial declarations. The above legal, as opposed to philosophical approach was intended to merely highlight the fact that ethical values are deeply entrenched in this area of the law and are becoming ever more explicitly referenced as authority for making particular decisions.[61] The most important values appear to be dignity, autonomy, sanctity of life, justice, and trust, all of which have a role in informing practices around consent, capacity to consent, and the determination of best interests in end-of-life situations as indicated in the introduction, the foregoing was also intended to underpin some recommendations for medical or family lawyers practising in this area. Given the increasing likelihood of clients facing such ends, our desire to avoid situations like in *Schiavo*, and the prevailing legal environment (which creates a powerfully useful space for ADs but contains patches of imprecision), it is appropriate to consider the lawyer's function, which must start from a recognition that he or she has an ethical duty to be competent and to serve his or her client in a conscientious, diligent, and efficient manner.[62] As a starting point, lawyers must accept that ethical values are more than minimally useful abstractions. Though they can be vague, reflection on them (even well short of deep philosophical introspection) and an appreciation of their relationship to medical decision-making will empower lawyers to better counsel clients in end-of-life situations, thereby enriching client decision-making.

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[61] Thus, the age-old "dodge" that courts have used (that is, the claim that they are arbiters of law, not ethics: see *Rodriguez*, *supra*, note 1, and *R. (on the application of Pretty) v. D.P.P.*, [2002] 1 A.C. 800 (H.L.), wherein Lord Hope, at para. 85, stated that it was not for the court to form a judgment on the ethical or moral issues raised, but rather to answer the questions of law asked) is less compelling in the medical context. More recent cases, including *R. (on the application of Burke)*, *supra*, note 18, suggest a greater willingness to engage with value-based and ethical terminology, and a growing direct judicial commitment to them.

[62] Chapter II, Competence and Quality of Service, *CBA Code of Professional Conduct* (Ottawa: CBA, 1987).

Lawyers must understand that most patients (and their SDMs) want a good death. Although this will vary from client to client, a recent study indicates that important elements of this include: trust and confidence in the treating physician, avoidance of unwanted life-support when there is little hope for meaningful recovery, honest communication of medical information, preparation for life's end (life review, conflict resolution, goodbyes), and avoidance of becoming a physical or emotional burden on family.[63] Unfortunately, studies have also found that end-of-life processes are often poorly managed due to insufficient information provided to SDMs.[64] This lack of information is a lacunae lawyers must endeavour to rectify, for the consequences to those navigating these difficult waters are indecision, inappropriate deference to others, and intractable disputes.[65]

As trusted participants in end-of-life processes, lawyers must do more to prepare clients, which means addressing the legal and ethical responsibilities of all parties, as well as the limits of their powers. An important mechanism for doing this, and for ensuring that disputes are minimised, is to employ ADs.[66] Bearing all of the above in mind, lawyers might adopt the following practices in preparing clients (and SDMs) for the potential ordeal ahead:

- The lawyer should encourage the client/patient to choose someone he or she is close to and trusts, using the same criteria for appointing a named second. Given that the majority of SDMs prefer to share decisional responsibility with physicians or defer responsibility to physicians altogether,[67] the lawyer should advise the client/patient to explore with the SDM the role he or she (the SDM) wishes to adopt (that is, active or passive with respect to decisional burden). Regardless of the decisional approach adopted, the SDM should be strongly encouraged to take an active approach insofar as maintaining

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[63] D. Heyland *et al.*, "Decision-Making in the ICU: Perspectives of the Substitute Decision-Maker" (2002), at www.springerlink.com [accessed 17 March 2006]. A similar ranking of elements was obtained from patient family members.

[64] S. Mitchell & F. Lawson, "Decision-Making for Long-Term Tube-Feeding in Cognitively Impaired Elderly People" (1999) 160 C.M.A.J. 1705-1709, who also cites R. Schonwetter *et al.*, "Tube-Feeding Decisions in Nursing Home Patients: Informed or Not?" (1996) 44 J. Am. Ger. Soc. S51

[65] On this latter point, it was lamented in *Wyatt v. Portsmouth NHS Trust*, [2005] E.W.C.A. Civ. 1181 (C.A.), that it is "a matter of regret" when the debate relating to the treatment of a seriously disabled person needs to be conducted in a courtroom. It is even more regrettable when the dispute dissolves into the mistrust and acrimony characterized by *Schiavo* (although the chances of a *Schiavo*-type frenzy occurring is reduced by the very different legal-political culture in Canada and the UK).

[66] Although we can see from the cases above, particularly *Grover*, that even having an AD does not eliminate the possibility of disputes necessitating judicial determination.

[67] D. Heyland *et al.*, *supra*, note 58.

regular contact with the client/patient and other supportive family and friends before incapacity and continuing to consult with that support network after incapacity is established.

- The lawyer should strongly advise (or ensure) that the SDM has adequate direction from the client/patient, thereby enhancing the SDM's authority if a dispute arises between the SDM and the client/patient's treatment team. This may mean facilitating a frank and open discussion between the client/patient and the SDM in the office. Such a discussion should explore: the values of each party (including those ethical values identified above), ideas around quality of life and functional tolerances, possible (and most feared) health scenarios, the parties' understanding of the treatment decisions which may be confronted, areas needing medical clarification, and most relevant statutory tests such as best interest factors.

- Given the likelihood of tube-feeding (or artificial nutrition and hydration) should the client/patient endure to old age,[68] the lawyer should foster a discussion (between client/patient and SDM) on this specific issue, particularly in light of the evidence suggesting its minimal effectiveness as a treatment for preventing aspiration or prolonging life, the relative burden it represents to patients, and the considerable expense it represents to the healthcare system (which may be a considerable factor in the medical facility's determination that it is either not medically indicated or a prudent use of limited resources given competing needs).[69]

- When drafting an AD, the lawyer should articulate the client/patient's general values and outlook on life and death, as well as scenario-specific guidance for SDMs that is as detailed as possible.

By doing this, lawyers improve their chances of promoting legally effective and ethically sound conduct that conforms to patient wishes in an otherwise highly emotive situation; they also improve their chances of being responsible officers of the court, effective counsellors, and valuable participants.

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[68] According to D. Heyland *et al.*, "What Matters Most in End-of-Life Care: Perceptions of Seriously Ill Patients and Their Family Members" (2006) 174 C.M.A.J. Online, over 70% of Canadians die in hospital as elderly patients. According to S. Mitchell & F. Lawson, *supra*, note 59, 10% of elderly people in chronic care facilities are tube-fed.

[69] S. Mitchell & F. Lawson, *ibid*, and the 12 studies cited therein. See S. Mitchell *et al.*, "A Decision Aid for Long-Term Tube Feeding in Cognitively Impaired Older Persons" (2001) 49 J.A.G.S. 313-316.