



A CRITIQUE OF ADVANCE DIRECTIVES AND ADVANCE DIRECTIVES LEGISLATION

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*The goal [of an advance directive] is to have open, serious, and intensive conversation between seriously ill people and their families, friends and physicians about the prospects of death and the way that everyone expects to behave as death comes closer. The underlying protection here is not in the specifics or what is said, but in the fact that people are talking.*¹

I. Preface

When I began this paper, I intended to write about the benefits of instructional directives. I believed that instructional directives could help stop the imposition of unwanted life support on patients who would prefer to die. Perhaps instructional directives could also help avoid family conflicts like the battle that happened over the death of Terry Schiavo.² I had even counselled people on the value of instructional directives while teaching a course on chronic disease

¹ R.A. Burt, *Death Is That Man Taking Names: Intersections of American Medicine, Law, and Culture* (Berkeley, CA: University of California Press, 2002) at 171.

² For more discussion about the Schiavo case, see *infra* note 94.

management.³ Without a doubt, I was a supporter of instructional directives.

So when I found some medical research that noted problems with instructional directives, I was skeptical. However, the evidence soon became overwhelming. There were numerous medical studies, all from credible journals, noting major practical problems in the actual use of instructional directives in health care settings. Several legal scholars also pointed out theoretical problems with the concept of autonomy and the ability to pre-determine good health care decisions. It quickly became clear to me that instructional directives were not all that I had thought them to be.

Advance directives affect the lives of dying patients and health care practitioners on a daily basis. Although the move towards greater patient autonomy may be worthy in theory, it appears to be falling short in the practice of instructional directives. There is room for more discussion and thought on this subject, in particular regarding better ways to help people make good health care decisions based on their personal values and wishes.

II. Introduction

An advance directive is a planning tool that is intended to give patients the ability to make life and death choices based on their personal values, goals and life plan. Advance directives can contain two parts: an instructional directive (or “living will”) and a proxy directive. Both directives come into force when a patient loses the ability to make his or her own decisions (or is deemed mentally incompetent). An instructional directive allows a patient to decide ahead of time what medical treatments she does and does not want to receive in the future.⁴ A proxy directive allows a patient to select

³ The six-week course is entitled “Chronic Disease Self-Management Program.” In BC, it is coordinated by the Centre on Aging at the University of Victoria. Online: The Centre on Aging <<http://www.coag.uvic.ca/cdsmp>>.

⁴ There is some uncertainty as to whether an instructional directive can be used only to refuse treatment or whether it can also be used to positively demand treatment. For example, the rejection of resuscitation is a common use of an instructional directive, a do-not-resuscitate (DNR)

someone else to make health care decisions on her behalf. This paper focuses on instructional directives—their development, their problems, and their regulation. The benefits and problems of proxy directives will not be analyzed in this paper.⁵

Instructional directives developed out of a clash of two factors: the development of life-sustaining medical technology and a societal shift that increasingly recognized the value of autonomy. People feared suffering a prolonged dying process where they were unnaturally kept alive on machines and tubes. Two major cases in the USA developed the law that patients have a right to determine their future health

order. But could an instructional directive demand that a patient always be resuscitated, no matter what the medical circumstances? In 2003, the Manitoba Law Reform Commission concluded that instructional directives should not be used to demand treatment that would otherwise be withheld. See Manitoba Law Reform Commission ["LRC"], *Withholding or Withdrawing Life Sustaining Medical Treatment*, No. 109 (2003). There is one case that is somewhat relevant to this issue. In *Sawatsky v. Riverview Health Centre Inc.*, [1998] 167 D.L.R. (4th) 359, 6 W.W.R. 298 (Man. Q.B.), a physician had put a DNR order on Mr. Sawatsky's chart despite fierce opposition from his spouse. The Manitoba Court of Queen's Bench allowed an injunction to temporarily remove the DNR order from the patient's chart. The decision clearly emphasized that the Court was allowing an order for an injunction, not ruling on the broader issue of physician capability to apply a DNR order in the face of proxy dissent. Mr. Sawatsky died before the case could be tried on its merits.

⁵ For a critique of proxy directives, see A.E. Buchanan et al., *Deciding for Others: The Ethics of Surrogate Decision making* (New York: Cambridge University Press, 1989). See also E.J. Emanuel et al., "Proxy Decision Making for Incompetent Patients. An Ethical and Empirical Analysis" (1992) 267(15) *Jama* 2067. See also J. Suhl et al., "Myth of Substituted Judgment. Surrogate Decision Making Regarding Life Support Is Unreliable" (1994) 154(1) *Arch Intern Med* 90. See also D.P. Sulmasy et al., "The Accuracy of Substituted Judgments in Patients with Terminal Diagnoses" (1998) 128(8) *Ann Intern Med* 621.



care.⁶ Two important cases in Canada established that wishes in an instructional directive should be followed, even if following the instructions could lead to a patient's death.⁷ The patient's right to self-determination should trump a doctor's wishes.

Starting in the mid-1990s, Canadian jurisdictions began passing legislation on instructional directives. Currently, several statutes in Canada directly regulate instructional directives, giving requirements for how old a person must be in order to make a valid directive and form requirements (i.e., signed, dated, etc.).⁸

Many legal scholars, public institutions and politicians have applauded instructional directives, arguing that they protect patient self-determination and autonomy.⁹ In theory, they have a good point, but medical research tells a very different story. Medical research shows that instructional directives may merely be adding a layer of confusion and legality to an already difficult end-of-life situation. In particular, this paper will outline the following problems with instructional directives: (1) people do not make them; (2) the information in instructional directives may not be clinically relevant; (3) the instructional directive may not reflect the current wishes of the patient; (4) patients generally lack the knowledge to make accurate treatment decisions; (5) even if they are made and are relevant, instructional directives may not affect treatment decisions; (6) other values (i.e., a physician's values or organizational values) may usurp

⁶ See *Matter of Quinlan*, 70 N.J. 10, 335 A.2d 647 (1976) [*Quinlan*] and *Cruzan v. Director, Missouri Department of Health*, 497 US 261, 110 SCt 2841 (1990) [*Cruzan*].

⁷ See *Malette v. Shulman*, (1990), 72 O.R. (2d) 417 (C.A.) [*Malette*] and *Fleming v. Reid*, (1991) 82 D.L.R. (4th) 298, 4 O.R. (3d) 74 [*Fleming*].

⁸ Further discussion of these statutes will be found at Part III. c, below.

⁹ See R. Astroff, "Who Lives, Who Dies, Who Decides?: Legal and Ethical Implications of Advance Directives" (1997) 7 W.R.L.S.I. 1. For a summary of current public approval for living wills see A. Fagerlin et al., "Enough: The Failure of the Living Will" (2004) *Hastings Center Report* 34, No. 2 30. But see also R. Dresser, "Precommitment: A Misguided Strategy for Securing Death with Dignity" (2003) 81(7) *Tex Law Rev* 1823.

the patient's values; and (7) legislation has confused the standard of when an instructional directive is applicable.

Legislation that regulates instructional directives may be a step in the wrong direction because it focuses on defining the narrow legal boundaries of a directive rather than encouraging its use as an instigator of conversation and thought. Instructional directives should move away from legal formalities and focus more on encouraging people to think about and discuss their goals and wishes for end-of-life care.

III. Development of Instructional Directives

Advance directives were not an issue before the development of life-sustaining treatments like ventilators, dialysis machines, antibiotics and feeding tubes.¹⁰ Before those technologies, if an individual suffered a cardiac arrest or caught pneumonia she was likely to die quickly. There were few treatment decisions to be made.¹¹

In the early twentieth century, new life-saving technologies were developed. These medical advances were primarily used to sustain lives, regardless of the patient's actual wishes.¹² As was noted by a physician in the Senate Special Committee's Report, "in this century, [physicians] have come to view our mandate to be to overcome death".¹³

Along with these medical advances came broad changes to the values of society, and individual liberty, personal security and bodily integrity became more important. The physician/patient relationship was changing from an authoritarian or paternalistic interaction to one

¹⁰ K.L. Kirschner, "When Written Advance Directives Are Not Enough" (2005) 21(1) Clin Geriatr Med 193 at 195.

¹¹ Law Reform Commission of Canada, Minister of Supply and Services Canada, *Euthanasia, Aiding Suicide and Cessation of Treatment*, No. 28 (1982) at 5.

¹² *Ibid.* at 5.

¹³ Senate of Canada, *Of Life and Death: Report of the Special Committee on Euthanasia and Assisted Suicide*, No. 33 (1995).

much more defined by equality and participation.¹⁴ Patients wanted more input into their treatment decisions.¹⁵ There was fear that new medical technologies could be used to unreasonably extend the dying process, leaving people unable to control their medical decisions.¹⁶ People feared “the prospect of dying away from home in impersonal and unfamiliar surroundings and of having to endure prolonged and often needless suffering”.¹⁷ As Robert Burt dramatically put it, people feared the “physician’s relentless warfare against death and their consequent infliction of terrible suffering on people who were inevitably and uncontrollably dying”.¹⁸

III.a American Developments

From the late 1970s to the early 1980s, the tension between the paternalistic application of life-saving treatment and the principle of personal autonomy entered public awareness. In 1976, the case of Karen Quinlan sparked public debate.¹⁹ Ms. Quinlan went into cardiac arrest when she was 21 and permanently lost consciousness due to brain damage. She was put on a ventilator to keep her alive. Her father sought a court order that would allow him to direct the ventilator to be removed, arguing that this was what Ms. Quinlan would have wanted. The New Jersey Supreme Court granted the order, ruling that patients have the right to decide whether to receive life-sustaining treatment.

After *Quinlan*, state and federal governments became interested in passing legislation that would protect the patient’s right to self-determination. The same year as *Quinlan*, California passed the *Natural*

¹⁴ Manitoba LRC, *Withholding or Withdrawing Life-Sustaining Medical Treatment*, *supra* note 3 at 6.

¹⁵ Manitoba LRC, *Substitute Consent to Health Care*, No. 110 (2004) at 5.

¹⁶ Manitoba LRC, *Self-Determination in Health Care (Living Wills and Health Care Proxies)*, No. 74 (1991) at 3.

¹⁷ G. Dworkin et al., *Euthanasia and Physician-Assisted Suicide* (Cambridge, UK: Cambridge University Press, 1998) at 84.

¹⁸ Burt, *supra* note 1 at 1.

¹⁹ *Quinlan*, *supra* note 6.

Death Act.²⁰ This was the first statute in North America that dealt with advance directives.

In 1990, the *Cruzan* case spurred on the development of advance directives.²¹ This case involved the application to withdraw the feeding tube from Ms. Cruzan, a patient who was in a permanent vegetative state. Similar to *Quinlan*, Ms. Cruzan's parents argued that Ms. Cruzan would have wanted the tube to be removed because she had previously stated that she would not want to "live as a vegetable". The Missouri Supreme Court ruled that Ms. Cruzan's feeding tube should not be removed. The Court ruled that there must be clear and convincing evidence of the patient's wish to have life-sustaining procedures withdrawn in order for treatment to be withdrawn from an incompetent patient. Oral statements must indicate a specific clinical situation and the particular intervention that is to be refused. Ms. Cruzan's prior statements did not meet that standard.

On appeal, the US Supreme Court upheld the Missouri ruling, holding that Missouri's "clear and convincing evidence" standard was constitutional.²² The Supreme Court indicated that each state is free to set standards for what will constitute evidence of a patient's preferred treatment. Other states, for instance New Jersey in *Quinlan*, are permitted to have a lower standard than Missouri's "clear and convincing evidence".

Few oral statements would meet the rigorous standard required by the Missouri Supreme Court. Hence, public policy promoted the creation of a written advance directive. By drawing up an instructional directive that complies with a legislated standard, a patient could feel confident that her wishes will be upheld.

In 1991, a federal law came into effect in the US that requires all hospitals and nursing homes to inquire at the time of admission as to

²⁰ *California Natural Death Act*, Cal. Health and Safety Code §7185-7195 (West 1976) (repealed 2000).

²¹ *Cruzan*, *supra* note 6.

²² *Cruzan*, *supra* note 6.



whether the patient has an advance directive.²³ If the patient does not have a directive, the institution is required to ask whether the patient would like one completed. It is left up to the individual states to regulate advance directives as they see fit. Since 1991, most states have revised or enacted laws on advance directives.²⁴

III.b Canadian Common Law Development

By the 1990s in Canada, the tension between respecting individual autonomy and preserving life was largely resolved.²⁵ Competent patients have the right to determine what shall be done with their bodies.²⁶ This right to self-determination includes the right to reject any treatment, including life-sustaining or life-saving measures.²⁷

In *Malette*, the Ontario Court of Appeal held that a competent patient can refuse medical treatment through an instructional directive. In that case, an emergency-room doctor gave a blood transfusion to a severely injured and unconscious woman. The critical factor was that the patient carried a card declaring her unwillingness to undergo a blood transfusion because of her religious convictions. Mrs. Malette survived, but she suffered mentally and emotionally when she found out that she had received a blood transfusion. Mrs. Malette sued Dr. Shulman for damages in battery. Despite the card being neither witnessed nor dated, the Court held that the instructions on the card should have been followed. Robins J.A. noted that “the right to

²³ *Patient Self-Determination Act*, Omnibus Budget Reconciliation Act of 1990, Pub L No. 101-508.

²⁴ B. Lo et al., “Resuscitating Advance Directives” (2004) 164(14) *Arch Intern Med* 1501-6.

²⁵ M.J. Dykeman, *Canadian Health Law Practice Manual* (Toronto: Butterworths, 2000) at 8.13.

²⁶ Justice Cardozo’s statement in *Schloendorff v. New York Hospital*, 211 N.Y.R. 125 (1914) at 129-130 is often quoted in this regard: “Every human being of adult years and sound mind has a right to determine what shall be done with his own body”.

²⁷ See Manitoba LRC, *Self-Determination in Health Care*, *supra* note 13 at 4. See also P.A. Singer et al., “Elective Use of Life-Sustaining Treatments in Internal Medicine” (1991) 36 *Adv Intern Med* 57.

determine what shall be done with one's own body is a fundamental right in our society. The concepts inherent in this right are the bedrock upon which the principles of self-determination and individual autonomy are based".²⁸ A patient's right to self-determination allows her the freedom to make choices that may seem to be against her best interests.

In *Fleming*, the Ontario Court of Appeal confirmed that instructional directives can be used to pre-emptively reject treatment. In *Fleming*, two psychiatric patients, while competent, refused a particular treatment. They intended for their refusal to be binding even if they were to become incompetent. The attending physician brought an application that would require the guardian to make treatment decisions based on the patient's best interests (in this case, receiving treatment) rather than upon their prior wishes (in this case, rejecting treatment). According to Robins J.A., the right of a competent adult to refuse medical treatment is entrenched in common law and in s. 7 of the *Canadian Charter of Rights and Freedoms*.²⁹ Regarding an instructional directive, Robins J.A. noted that:

A patient ... may specify in advance his or her refusal to consent to the proposed treatment. ... This right must be honored, even though the treatment may be beneficial or necessary to preserve the patient's life or health, and regardless of how ill-advised the patient's decision may appear to others.³⁰

III.c Canadian Legislation

There is currently no federal law that governs advance directives.³¹ In its 1995 report, "Of Life and Death," the Senate Special Committee

²⁸ *Malette*, *supra* note 7 at 432.

²⁹ *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act*, 1982, being Schedule B to the *Canada Act* (U.K.), 1982, c. 11 [*Charter*]. See s. 7: "Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice".

³⁰ *Fleming*, *supra* note 7 at para. 34.

³¹ The federal government likely does not have jurisdiction to regulate in this area. Although "health" is not specifically designated to either provincial or federal jurisdiction, it is generally accepted that the provinces

on Euthanasia and Assisted Suicide recommended that all jurisdictions that did not have advance directive laws adopt such legislation.³²

Currently, five Canadian provinces have legislation that specifically regulates instructional directives: Alberta,³³ Saskatchewan,³⁴ Manitoba,³⁵ Newfoundland and Labrador³⁶ and PEI.³⁷ The statutes reflect the intent to make instructional directives formal and binding. The statutes vary in the age minimum required to make a valid directive. In Alberta, a person must be over 18.³⁸ In Saskatchewan,

have exclusive jurisdiction over the supply of health goods and services pursuant to ss. 92(7) (hospitals), 92(13) (property and civil rights) and 92(16) (matters of a merely local or private nature) of the *Constitution Act, 1867*. Instructional directives would likely fall into the category of s. 92(13) (property and civil rights) because they are contractual in nature, and thus would be under the jurisdiction of the provinces. See J.G. Downie et al., *Canadian Health Law and Policy* (Toronto: Butterworths, 2002) at 12.

³² Senate of Canada, *supra* note 13 at 50.

³³ *Personal Directives Act*, S.A. 1996 c. P-4.03 [*AB Act*].

³⁴ *The Health Care Directives and Substitute Health Care Decision Makers Act*, S.S. 1997, c. H-001 [*SK Act*].

³⁵ *Health Care Directives Act*, C.C.S.M. 1992, c. H-27 [*MB Act*].

³⁶ *Advance Health Care Directives and the Appointment of Substitute Decision Makers Act*, S.N. 1995, c. A-4.1 [*PEI Act*].

³⁷ *Consent to Treatment and Health Care Directives Act*, S.P.E.I. 1996, c. 10 [*NL Act*].

³⁸ *AB Act*, *supra* note 33 at s. 5(1).

Manitoba and PEI, a person must be over 16.³⁹ Newfoundland and Labrador does not have a minimum age requirement.⁴⁰

The statutes also vary in the form that the instructional directive must take (i.e., signed, witnessed and dated). In Alberta⁴¹ and PEI,⁴² the directive must be signed by the maker, dated and witnessed by someone other than the spouse of the person. In Saskatchewan⁴³ and Manitoba,⁴⁴ the directive must be in writing, signed by the maker and dated. There is no requirement for witnessing unless the patient cannot sign the document herself. In Newfoundland and Labrador, an instructional directive must be in writing, signed by the maker and witnessed by independent persons;⁴⁵ there is no dating requirement.

Most of the other jurisdictions in Canada have some legislation that covers instructional directives by implication. For example, statutes in BC⁴⁶ and Ontario⁴⁷ require a health care provider to respect

³⁹ *SK Act*, *supra* note 34 at s. 2(1)(c); *MB Act*, *supra* note 35 at s.5.

⁴⁰ The statute instead focuses on competency. See *NL Act*, *supra* note 37 at s. 3(1): “a person who is competent may make an advance health care directive setting out the person's instructions regarding his or her health care treatment or setting out general principles regarding the type of health care the person wants”.

⁴¹ *AB Act*, *supra* note 33 at s. 5(1).

⁴² *PEI Act*, *supra* note 36 at s. 21.

⁴³ *SK Act*, *supra* note 34 at s. 6.

⁴⁴ *MB Act*, *supra* note 35 at s. 8.

⁴⁵ *NL Act*, *supra* note 37 at s. 6(1).

⁴⁶ *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c. 181, s. 12.1 [*BC Act*]: “A health care provider must not provide health care under s. 12 if the health care provider has reasonable grounds to believe that the person, while capable and after attaining 19 years of age, expressed an instruction or wish applicable to the circumstances to refuse consent of the health care”.

⁴⁷ *Health Care Consent Act*, S.O. 1996, c. 2, s. 5: “A health care provider shall not administer treatment under s. 25 [emergency treatment] if the health care provider has reasonable grounds to believe that the person,



instructional directives in emergency care settings. The health care provider must not provide treatment if there are “reasonable grounds” to believe that a person expressed an “instruction or wish” to refuse specific treatment. The use of the word “wish” indicates that an oral statement may be sufficient. The only express limitation is that the instruction or wish must be made after the person is 19 years old in BC, or 16 years old in Ontario.

BC,⁴⁸ Ontario,⁴⁹ Quebec⁵⁰ and the Yukon⁵¹ have proxy legislation that gives *de facto* protection of instructional directives. The proxy legislation generally requires the proxy to abide by a patient’s prior known wishes, but does not require that those wishes be expressed in a specific format. Instructional directives that are in writing, signed and dated would certainly constitute evidence of a prior wish. The broad language of the proxy directive statutes implies that oral statements will suffice as indication of a patient’s wishes.

In Nova Scotia, there is no legislation that specifically requires a health care provider or proxy to abide by a patient’s prior wishes.⁵² There is no legislation regulating proxy or instructional directives in New Brunswick, the Northwest Territories or Nunavut.

while capable and after attaining 16 years of age, expressed a wish applicable to the circumstances to refuse to consent to the treatment”.

⁴⁸ *BC Act*, *supra* note 46 at s. 19(2)(a).

⁴⁹ *Substitute Decisions Act*, S.O. 1992, c. 30, ss. 66(3).

⁵⁰ *Civil Code of Quebec*, S.Q. 1991 c. 64, art. 12.

⁵¹ *Health Act*, R.S.Y. 2002, c. 106, s. 45(5).

⁵² There is legislation covering proxy directives, but it does not specifically require the proxy to abide by the patient’s prior expressed wishes. See *Medical Consent Act*, R.S.N.S. 1989, c. 279.

There are currently two main templates for advanced directives in Canada: the "Living Will"⁵³ and a document called "Let Me Decide".⁵⁴ Both advance directives, if completed fully and properly, will meet the standards of all Canadian jurisdictions.

IV. Problems With Instructional Directives

1) People do not make them

Advance directives have been endorsed in the US for over 30 years, and since 1991, federal legislation has required that health care organizations inform patients of their right to make a directive. Despite this high profile, relatively few people in the US complete advance directives. A 2005 article noted that medical research has indicated that only 5 to 15 percent of people in the US have advance directives.⁵⁵ Studies have found only a small increase in the percentage of the public who have executed an advance directive since the introduction of the federal legislation in 1991.⁵⁶ Several surveys have indicated that many people know about advance directives but few actually complete them.⁵⁷

⁵³ Created by the Joint Centre for Bioethics at the University of Toronto. The template is available online: Joint Centre for Bioethics <http://www.utoronto.ca/jcb/outreach/living_wills.htm>.

⁵⁴ Created by a Canadian doctor, Dr Molloy. See W. Molloy, *Let Me Decide* (Troy, ON: Newgrange Press, Orkney House. 1989). See also W. Molloy, *Let Me Decide: The Health and Personal Care Directive That Speaks for You When You Can't* (Victoria, BC: Vancouver Island Health Authority, 2004). Online: Vancouver Island Health Authority <http://www.viha.ca/healthpoint/let_me_decide/pdf/LMD_AdvanceDirective_New_Form.pdf>.

⁵⁵ Kirschner, *supra* note 10 at 196.

⁵⁶ E. Larson and T. Eaton, "The Limits of Advance Directives: A History and Assessment of the Patient Self-Determination Act" (1997) 32 Wake Forest Law Review 249.

⁵⁷ E.R. Gamble et al., "Knowledge, Attitudes, and Behavior of Elderly Persons Regarding Living Wills" (1991) 151(2) Arch Intern Med 277. See also J.L. Holley et al., "Factors Influencing Dialysis Patients' Completion of Advance Directives" (1997) 30(3) Am J Kidney Dis 356.

There are many factors that could explain why the use of advance directives is so low.⁵⁸ The process of creating an advance directive may be time consuming and psychologically difficult. People generally do not like to think about their own death, let alone make detailed plans. Some people procrastinate, while others assume instructional directives are only for the elderly or infirm.

People may not issue instructional directives because they simply do not want to make end-of-life decisions alone. In a study of dialysis patients, approximately one-third of the patients said their directives should be followed strictly, another third said their families and physicians should have some input in the decision, and the remainder said their families and physicians should have "complete leeway" to override their directives.⁵⁹ In another study, researchers found that most of their patients did not want to make final resuscitation decisions, but instead preferred to rely on their doctor's choices.⁶⁰

That people do not want to make their own treatment decisions is perhaps one of the most interesting reasons for the low use of instructional directives. If people do not want to make their own choices, then where does this leave theories of self-determination and autonomy? The proponents of self-determination have fought precisely so that people can have their medical choices respected. And yet studies show that people do not necessarily want to make final choices in regard to end-of-life decisions. As Robert Burt recently noted, "applying the autonomy framework in end-of-life decision-making has had little practical effect and much fictitious

⁵⁸ For a more detailed analysis of the reasons why people may not make instructional directives, see Fagerlin et al., *supra* note 8.

⁵⁹ A. Sehgal et al., "How Strictly Do Dialysis Patients Want Their Advance Directives Followed?" (1992) 267(1) *Jama* 59.

⁶⁰ C.M. Puchalski et al., "Patients Who Want Their Family and Physician to Make Resuscitation Decisions for Them: Observations from Support and Help. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. Hospitalized Elderly Longitudinal Project" (2000) 48(5 Suppl) *J Am Geriatr Soc* S84. See also S. Isaacs et al., *To Improve Health and Health Care 1997: The Robert Wood Johnson Foundation Anthology* (1997), online: Robert Wood Johnson Foundation <<http://www.rwjf.org/files/publications/books/1997/index.html>>.



posturing. Efforts to persuade people to execute advance directives to protect their autonomy if they should become incompetent have essentially failed".⁶¹

2) Information May Not Be Clinically Relevant

Empirical studies and physician accounts have repeatedly shown that instructional directives do not give physicians a clinically relevant guideline. For example, some directives use vague statements such as "take no heroic measures" or "continue treatment only if the benefits outweigh the burdens".⁶² Even instructional directives that focus on specific interventions may fail to guide a physician because not all treatment situations fit neatly into one of the anticipated scenarios.⁶³

3) It May Not Reflect Current Wishes

People change their minds frequently. Kirshner notes that "[a]s dynamic, evolving being, we ... frequently change our minds about issues as inconsequential as our favorite colors or foods and issues as significant as where we live, whom we marry and how we choose to spend our time".⁶⁴ Studies have shown that people also frequently change their minds while in the midst of dealing with a medical problem. In situations where patients are seriously ill, the trend is for people to change their minds in favour of receiving more treatment.⁶⁵

⁶¹ R.A. Burt, "The End of Autonomy. Improving End of Life Care: Why Has It Been So Difficult?" (2005) 35(6) Hastings Center Special Report 9.

⁶² M. Addison, "Living Wills/Advance Directives—a Physician's View" (1991) 1 Health Law Review 9.

⁶³ A.S. Brett, "Limitations of Listing Specific Medical Interventions in Advance Directives" (1991) 266(6) Jama 825.

⁶⁴ Kirshner, *supra* note 10 at 197.

⁶⁵ J.S. Weissman et al., "The Stability of Preferences for Life-Sustaining Care among Persons with Aids in the Boston Health Study" (1999) 19(1) Med Decis Making 16. See also K.E. Rosenfeld et al., "Factors Associated with Change in Resuscitation Preference of Seriously Ill Patients. The Support Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments" (1996) 156(14) Arch Intern Med 1558. See also M.A. Lee et al., "Do Patients' Treatment Decisions Match Advance Statements of Their Preferences?" (1998) 9(3) J Clin Ethics 258.



To a healthy and active person, the thought of being confined to a wheelchair may seem a fate worse than death. But when placed in the midst of an illness, what once was unthinkable may become acceptable.⁶⁶

If a directive does not express current wishes, then it may be doing little to support self-determination and autonomy. In fact, the directive may have the opposite effect, binding people to decisions they no longer endorse. The authors of *Canadian Medical Law* conclude that creating an instructional directive “is really tantamount to gazing into a crystal ball, particularly for one who is in general good health when filling out the directive”.⁶⁷

4) Patients Lack the Knowledge to Make Good Treatment Decisions

Presentation of the medical scenario can have a huge impact on the decisions of the patient. For example, one study showed that even just changing the language from a “90 percent chance of life” to a “10 percent chance of death” made people change their minds on treatment decisions.⁶⁸ In another study, 201 seniors were asked for their treatment decisions given various outcomes. Seventy-seven percent changed their minds at least once when given the same

⁶⁶ For an insightful narrative on this subject, see Nancy Mairs, *Waist High in the World: A Life Among the Nondisabled* (Boston, MA: Beacon Press, 1996). “Everybody well or ill, disabled or not, imagines a boundary of suffering and loss beyond which, she or he is certain, life will no longer be worth living. I know that I do. I also know that my line, far from being scored in stone, has inched across the sands of my life: at various times, I could not possibly do without long walks on the beach or rambles through the woods; use a cane, a brace, a wheelchair; stop teaching; let someone else put on and take off my underwear. One at a time, with the encouragement of others, I have taken each of these (highly figurative) steps... . Meanwhile, I go on being, now more than ever, the woman I once thought I could never bear to be”.

⁶⁷ B. Sniderman et al., *Canadian Medical Law: An Introduction for Physicians, Nurses and Other Health Care Professionals* (Scarborough, ON: Carswell, 2003).

⁶⁸ Brett, *supra* note 63.



scenario but different valence of presentation.⁶⁹ These studies question whether instruction directives really reflect what the patient wants or are simply a reflection of the presentation of information.

A further problem with instructional directives is the patient's potential lack of medical knowledge. One medical researcher, Dr. Brett, points out that "various combinations of preselected interventions ... may contradict the patient's goals or suggest unusual patterns of medical practice".⁷⁰ The intervention-focused directive runs the risk of promoting the selection or rejection of interventions because of their inherent characteristics rather than as appropriate means to the ends that the patient would have wanted.⁷¹

5) It May Not Affect Treatment Decisions

Even if an instructional directive has been made, there is no guarantee that it will ever get to the appropriate physician at the appropriate time. Practically, instructional directives may be made years in advance of any health care treatment. The existence, let alone location, of an instructional directive may be unknown to the attending physicians and family members. If admitted to an emergency room, a patient may be too overwhelmed with the circumstances to mention their advance directive.⁷² One study found that only 26 percent of patients who had previously executed advance directives had their directives recognized during their hospitalization.⁷³

⁶⁹ T.R. Malloy et al., "The Influence of Treatment Descriptions on Advance Medical Directive Decisions" (1992) 40(12) J Am Geriatr Soc 1255.

⁷⁰ Brett, *supra* note 63.

⁷¹ A. Moxey et al., "Describing Treatment Effects to Patients" (2003) 18(11) J Gen Intern Med 948.

⁷² R.S. Morrison et al., "The Inaccessibility of Advance Directives on Transfer from Ambulatory to Acute Care Settings" (1995) 274(6) Jama 478.

⁷³ *Ibid.*



The most damning research on instructional directives comes from the SUPPORT study, the largest study to date of dying people in America.⁷⁴ The main researchers of the SUPPORT data conclude that

[advance directives] were ineffectual in shaping care. In fact, the current practice of advance directive use failed at every key juncture. ... Our intervention was successful in getting virtually all advance directives recorded. However, they still had no effect upon decision making.⁷⁵

6) Other Values May Usurp a Directive

Even if the instructional directive is on the patient's chart and the doctor has read it, the values of the physician may usurp the values of the patient.⁷⁶ One study found that a patient's preferences were respected as long as the physician thought that the patient's choice

⁷⁴ The SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment) study involved over 9000 very sick patients in five different hospitals over a period of six years. The study received funding of approximately \$29 million from the Robert Wood Johnson Foundation. The study involved two phases: an initial phase that identified problems in the care of dying people, and a second phase that attempted to correct those problems. The second phase was carried out through the intervention of specially trained nurses who spent all their time counselling patients and families about treatment options. A large part of each nurse's job was to communicate the preferences and the prognosis between physicians and patients. Despite this intervention, the study found little improvement in the recognition of patient wishes. See "A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (Support). The Support Principal Investigators" (1995) 274(20) *Jama* 1591.

⁷⁵ Isaacs, *supra* note 60.

⁷⁶ D. Orentlicher, "The Illusion of Patient Choice in End-of-Life Decisions" (1992) 267(15) *Jama* 2101.

resulted in the best decision.⁷⁷ Another study found that physicians are more inclined to talk with patients who are most like them.⁷⁸

The values and policies of the health care institution may also usurp the patient's advance directive. The Dalhousie End-of-life Project noted that

[s]ome policies ... suggest that the organization can place limits on whether a decision made in the process of advance care planning will be considered valid within that facility. For example, one facility suggests that an advance directive will be respected as long as it does not conflict with the mission of the organization ... one policy explicitly states that while a patient can make an advance directive, no guarantees are given as to whether it will be respected.⁷⁹

7) Legislation Confuses the Standard

Some instructional directive statutes have standards that appear to be higher than the common law. For example, as discussed above, the Newfoundland and Labrador statute requires an instructional directive to be in writing, signed and witnessed by two independent persons. The Saskatchewan statute requires a directive to be in writing, signed and dated. Yet the common law appears to have a lower standard. For example, the card in *Malette* was upheld as a valid directive that should have been followed even though it was not dated or witnessed. In *Fleming*, the patient's wishes were not in a legal format, but were discovered through a review of the clinical records.⁸⁰

⁷⁷ M. Danis et al., "A Prospective Study of Advance Directives for Life-Sustaining Care" (1991) 324(13) N Engl J Med 882.

⁷⁸ T.R. Malloy et al, *How Interventions Are Described Affects Patients' Decisions About Life-Sustaining Treatment*, in American Geriatric Society/American Federation For Aging Research Annual Scientific Meeting, 1991 Program (Abstract A2).

⁷⁹ Health Law Institute, Dalhousie University, "Review of Withholding and Withdrawal of Potentially Life-Sustaining Treatment Policies in Canada" (2004) Online: <http://as01.ucis.dal.ca/dhli/cmp_documents/documents/ACFbodROQ.pdf> at 54.

⁸⁰ See *Fleming*, *supra* note 7.

Case law in the US indicates that some states have a specific standard for allowing when a patient's prior wishes will be considered. For example, in Missouri the standard is that there must be clear and convincing evidence of the patient's prior wish. As happened in the *Cruzan* case, oral expressions of interest would likely not meet the standard. How would oral statements of preference be treated in Canada?

An unreported Alberta case from 1999 gives some direction in this area.⁸¹ In that case, the 47-year-old Constable Durksen was in a comatose state after a major car accident. The Court was asked for advice on whether life-sustaining treatment could be discontinued. The patient had not made an advance directive, but anecdotal evidence from family and friends indicated that he would not want to receive life support.⁸² The Court took this anecdotal evidence into consideration, and allowed the removal of life support.

At the time of Constable Durksen's case, Alberta's *Personal Directives Act* was in force.⁸³ It required that a personal directive be in writing, signed and dated.⁸⁴ Clearly Constable Durksen's comments to his family and friends did not meet the standard of a statutory directive. Yet the Court considered his commentary as persuasive evidence. This case indicates that Canadian courts may apply a standard lower than statute when determining whether a patient's prior wishes should be considered.

There are four other sources of evidence indicating that legislation may not be raising the standard for recognizing advance directives: LRC reports, legislative debates, principles of statutory interpretation and *Charter* rights.

⁸¹ *In the Matter of Robert Kenneth Durksen, Dependent Adult, Surrogate Court of Alberta, Lethbridge/MacLeod* (16 Sept 1999), court file DA06-02070, cited in G. Godlovitch et al., "Discontinuing Life Support in Comatose Patients: An Example from Canadian Case Law" (2005) 172(9) *Canadian Medical Association Journal* at 1172-3.

⁸² Constable Durksen had witnessed many injuries and fatal car accidents in his work, and had discussed his views with friends and family.

⁸³ *Personal Directives Act*, S.A. 1996, c. P-4.03, now R.S.A. 2000, c. P-6

⁸⁴ *Ibid.* at s. 5(1).

Some provinces appear to have dealt specifically with how an instructional directive statute interacts with the common law. For example, in 1991, the Manitoba LRC stated that the “common law presently recognizes some directions given in advance in respect of future medical treatment. The Commissions’ proposed scheme would not affect the legality of such directions, nor would it impede the courts from expanding upon them”.⁸⁵ Indeed, the Manitoba statute now states that “nothing in this Act abrogates or derogates from any rights or responsibilities conferred by statute or common law”.⁸⁶

In Saskatchewan, there may be an argument that the statute was not intended to raise the common law standard. In debating the *Saskatchewan Act* in the legislature, the Honourable Mr. Cline said that “health care directives legislation reinforces the personal autonomy of Saskatchewan residents. It recognizes the importance of self-determination, and it also recognizes that individuals want to exercise choice in their medical treatment”.⁸⁷ These statements can be used to show that instructional directive legislation was passed in order to affirm patient rights, not to derogate from the common law standard.

There may also be an argument that statutory interpretation indicates that statute should not raise the common law standard. Ruth Sullivan notes that “it is presumed that the legislature does not intend to change the existing law. This presumption was used historically to shelter the common law from unwanted statutory intrusions. It is used in modern courts to resist any weakening or exclusion of principles, whether common law or statutory, that are considered important by the courts”.⁸⁸

Finally, there is indication that the principles of self-determination and autonomy are entrenched in the *Charter* and cannot be changed

⁸⁵ Manitoba LRC, *Self-Determination in Health Care*, *supra* note 13 at 4.

⁸⁶ *MB Act*, *supra* note 35 at s. 25.

⁸⁷ Saskatchewan, Legislative Assembly, *Hansard*, 1591 (13 May 1997) at 1618 (Hon. Eric Cline).

⁸⁸ R. Sullivan, *Statutory Interpretation* (Concord, ON: Irwin Law, 1997) at 182.



by provincial statute. In *A.M. v. Benes*,⁸⁹ the Court reviewed a decision of a parent to refuse electro-convulsive therapy treatment for her schizophrenic adult daughter. The Board argued that the mother had not complied with s. 21 of the *Ontario Health Care Consent Act* (namely, that she act in the best interests of the daughter). Justice Shulman looked at the interaction between the common law (*Malette* and *Fleming*), statute and the *Charter*:

I want to stress the constitutional entrenchment because there are in the materials filed on behalf of the Attorney General repeated references to provisions of the Act said to be "codifications" of the related common law. Historically, where there was no *Charter* dimension, statutory codifications have usually supplanted, within the ambit of the statute, the pre-existing substantive common law. ... It is in my opinion crucially important to stress that the patient's rights here in issue are fundamental, constitutionally entrenched rights of a high order and that no amount of "codification" will diminish those rights unless the asserted codification meets the tests of the *Charter*.

From Justice Shulman's comments, it could be argued that a directive that does not meet the legislated standard should be upheld on constitutional grounds.⁹⁰ In particular, the right to security of the person in s. 7 of the *Charter* guarantees physical and psychological

⁸⁹ *M. (A.) v. Benes* (1998), 166 DLR (4th) 658 (Ont. Ct. Gen. Div.), add'l reasons at (1998), 173 DLR (4th) 758 (Ont. Ct. Gen. Div.), rev'd on other grounds (1999), 180 DLR (4th) 72 (O.C.A.).

⁹⁰ The right to refuse treatment via advance directives may be protected by several sections of the *Charter*. See s. 2(a) ("Everyone has the following fundamental freedoms: a) freedom of conscience and religion") or s. 15 ("Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability") or s. 7 ("Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice"). A claim under s. 2(a) or s. 15 would require a very specific factual basis in order to succeed. Section 7 was successfully argued in *Fleming* and may offer the strongest constitutional grounds.

integrity.⁹¹ In *R v. Morgentaler*, the Supreme Court of Canada noted that “the law has long recognized that the human body ought to be protected from interference by others ... with the advance of the *Charter*, security of the person has been elevated to the status of a constitutional norm”.⁹²

Although persuasive evidence exists that statute was not meant to raise the standard on advance directives, there is some support for the opposite conclusion. Robins J.A. makes the following observation in *Fleming*:

In my view, no objection can be taken to procedural requirements designed to determine more accurately the intended effect or scope of an incompetent patient's prior competent wishes or instructions. As the Act now stands, the substitute consent-giver's decision must be governed by wishes which may range from an isolated or casual statement of refusal to reliable and informed instructions based on the patient's knowledge of the effect of the drug on him or her. Furthermore, there may be questions as to the clarity or currency of the wishes, their applicability to the patient's present circumstances, and whether they have been revoked or revised by subsequent wishes or a subsequently accepted treatment program. The resolution of questions of this nature is patently a matter for legislative action.⁹³

V. Conclusions

There seems to be a strong case that legislation is not imposing a higher standard on when an instructional directive should be followed. If the common law provides a more flexible standard, then what is the purpose of instructional directive legislation? One purpose may be to boost the confidence of members of the public in their ability to determine their own end-of-life care. With the publicity given to the *Quinlan* case in the 1970s, and recently the *Schiavo* case in

⁹¹ See *R v. Morgentaler*, [1998] S.C.R. 30 [*Morgentaler*]. *Rodriguez v. British Columbia*, [1993] 3 S.C.R. 519.

⁹² *Morgentaler*, *supra* note 91 at para. 5.

⁹³ *Fleming*, *supra* note 7 at para. 57.



Florida,⁹⁴ people fear what will happen to them if they become incompetent. Legislation may be a convenient way to display support for self-determination and autonomy.

Legislation may put forth a good public face, but it does not resolve many of the issues with instructional directives. As argued above, just because an instructional directive is legally binding, does not mean that it will be used or that it will affect treatment decisions. In fact, legislation may be serving as a hindrance to improving the treatment of dying people because it focuses on form, not content. At best, instructional directive legislation gives a veneer of protecting patient autonomy. At worst, instructional directive legislation confuses standards, gives the maker a false sense of security and does nothing towards protecting patient autonomy.

Perhaps instead of legislation, efforts should be put into more public dialogue and awareness about end-of-life care issues surrounding instructional directives. As Dr. Kirschner concludes in her recent article, “advance directives should be seen as tools that facilitate making difficult decisions in uncertain times, not as static, dogmatically binding documents”.⁹⁵

⁹⁴ In 1990, Terri Schiavo's heart stopped. She was resuscitated, but she suffered severe brain damage and was unable to feed herself. Her husband was appointed her guardian, and asked the Court to remove her feeding tube. Ms. Schiavo's parents vehemently objected to removing the tube. The issue became highly publicized and was much debated. Eventually, her husband won a court battle, her feeding tube was removed, and she died. See *Schindler v. Schiavo* (2003), 851 So.2d 182 (Fla. App. 2 Dist.). See also R. Dresser, "*Schiavo*: A Hard Case Makes Questionable Law" (2004) Hastings Center Report 8.

⁹⁵ Kirschner, *supra* note 10.