

**LEGAL STATUS OF ADVANCE HEALTH CARE DIRECTIVES:
PROFESSIONAL ATTITUDES REGARDING COMPLIANCE**

By

KAREN JANET LEE

A Thesis Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements for the Degree of

MASTER OF LAWS

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ABSTRACT

Advance health care directives are a legal mechanism allowing patients to be in control of medical treatment decision-making in the event of future decisional incompetency. Three hundred health care professionals were surveyed to determine their knowledge and understanding of advance health care directives. The study cohort was comprised of a variety of health care team members including physicians, nurses, technologists, and pharmacists. The study consisted of both qualitative and quantitative components. The quantitative component consisted of 57 questions requiring a simple yes-no response. These questions were categorized to determine respondents' awareness and knowledge level of advance directives, actual experience with implementation of such directives, and comfort levels in implementing such directives in a variety of hypothetical clinical scenarios involving adult patients in medical, surgical and psychiatric clinical settings. The qualitative component consisted of respondents' definitions of relevant terminology and examples of their actual or proposed advance directives.

The study results suggest that an overwhelming number of health care professionals support patient autonomy and decision-making by way of advance health care directives. They demonstrate a good understanding of some aspects of the legal status of advance directives but limited understanding of others. They may have difficulty with the actual implementation of advance directives, especially those involving so-called "irrational" treatment choices and those involving the refusal of medical treatment with a high probability of success as well as those requesting withholding of medical treatment. Due to lack of consensus with respect to terminology relevant to the area of advance directives and lack of understanding of the concept of proportionality and the benefits-burdens test, HCPs may experience difficulty interpreting patients' directives. Health care professionals and emergency medical services personnel were found to value patient autonomy and lawyers express were found to express concerns regarding clients' best interests to a greater extent than anticipated. All professional groups expressed a high degree of concern and meticulousness in ensuring that patients' or clients' treatment choices reflect their true wishes.

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Introduction

The purpose of this thesis is to examine issues raised by the implementation of advance health care directives by health care professionals.

Part A introduces advance health care directives. Chapter 1 provides an introduction to medical decision-making and underlying biomedical ethical principles. Chapter 2 defines and details the origin, meaning and purpose of advance health care directives in a historico-legal context.

Part B describes the current status of the law relating to advance directives. Chapter 3 focuses on Canadian law while Chapter 4 concentrates on four other common law jurisdictions: the United States, Great Britain, Australia and New Zealand.

Part C explores the relevance of advance directives law to health care and legal professionals. Chapter 5 presents an empirical analysis of perceptions, attitudes, and opinions of health care professionals, emergency medical services personnel, and lawyers. Chapter 5 discusses study format, methodology and results and Chapter 6 presents recommendations and proposals for refining Manitoba's advance directives legislation.

PART A

ADVANCE HEALTH CARE DIRECTIVES: INTRODUCTION

Chapter 1

Introduction to Medical Decision-Making

1) Introduction¹

Western civilization enjoys unparalleled technological innovation, especially in medicine. Today we are able to treat conditions that would have once meant certain death. We can keep hearts beating and lungs breathing mechanically when the brain cells controlling these bodily functions have ceased to function. We can replace diseased body parts with healthy organs. We can induce hearts to beat anew by inserting internal pacemakers and automated defibrillators into cardiac tissue. We can even offer a new heart when all else fails. These advances provide unquestionable benefits, but they also present quandaries, conundrums and dilemmas:

Until recently there was no doubt what was life and what was death. A man was dead if he stopped breathing and his heart stopped beating....Apart from cases of unlawful homicide, death occurred automatically in the course of nature when the natural functions of the body failed to sustain the lungs and the heart....Recent developments in medical science have fundamentally affected these previous certainties. In medicine, the cessation of breathing or of heartbeat is no longer death. By the use of a ventilator, lungs which in the unaided course of nature would have stopped breathing can be made to breathe, thereby sustaining the heartbeat. Those...who would previously

¹A Glossary of Relevant Medical Terminology is provided in Appendix A.

have died through inability to swallow food can be kept alive by artificial feeding. This has led the medical profession to redefine death.²

Prior to the advent of mechanical ventilation, people with neurological conditions such as Guillain-Barre syndrome and amyotrophic lateral sclerosis (ALS) would have died a natural death as a result of the disease process. Guillain-Barre syndrome paralyzes respiratory muscles. ALS destroys spinal cord and brain stem cells, ultimately resulting in total paralysis. People affected by these conditions experience no alteration in cognition; they are aware of their surroundings but unable to move or to breathe unaided.³ With the use of mechanical ventilators, it is possible to keep them artificially alive for many years. Is the use of mechanical ventilation in these cases truly a medical advance or is it a means of prolonging the inevitable, often engendering suffering and indignity in the process?

Locked-in syndrome arises as a result of focal brain stem lesions. Affected individuals are totally paralyzed in limbs and speech but fully conscious and totally aware of their surroundings, able to breathe unaided by mechanical ventilation but unable to swallow and, therefore, dependent on artificial hydration and nutrition.⁴ Is a seemingly

²Airedale N.H.S. v. Bland, [1993] 2 W.L.R. 316 (H.L.), at 380.

³Aminoff, M.J. "Nervous System" in Tierney, L.M. Jr., S.J. McPhee and M.A. Papadakis (Eds.) Current Medical Diagnosis and Treatment 1995 Norwalk, Conn.: Appleton, at 872.

⁴Ibid.

innocuous piece of technology such as a feeding tube really beneficial in these cases or merely a means of prolonging an inevitable process, inflicting indignity and suffering?

The court, in Bland, poignantly describes a person in a persistent vegetative state (PVS):

...the PVS patient continues to breathe unaided and his digestion continues to function. But although his eyes are open, he cannot see. He cannot hear. Although capable of reflex movement, particularly in response to painful stimuli, the patient is incapable of voluntary movement and can feel no pain. He cannot taste or smell. He cannot speak or communicate in any way. He has no cognitive function and can thus feel no emotion, whether pleasure or distress.⁵

This condition arises when a person experiences cerebral oxygen deprivation which induces irreversible cellular damage to the cerebral cortex, which governs sensorimotor and higher functions such as reasoning and intellect. However, it leaves the brain stem -- governing the physiological functions of respiration, circulation and digestion -- intact. PVS patients do not require mechanical ventilators to breathe but are unable to swallow and require artificial hydration and nutrition for survival.⁶

These examples are illustrative of complex clinical dilemmas which have arisen as a result of medico-technological advances.

⁵Bland, *supra* note 2, at 363-364.

⁶Multi-Society Task Force on PVS. Medical Aspects of the Persistent Vegetative State (Part I) 1994 330 N.E.J.M. 1499, at 1499-1501.

We are awed by medical technology and the power it can exert over our lives. Yet we must not allow technology to be our master. While we marvel at these breathtaking advances, as a society, we "need to control medical technology to assure that it will serve human needs and values and not follow a momentum of its own."⁷ We need to recognize that medicine is not merely an aggregate of technical skills exercised by efficient clinicians. Medicine has to do with ethics and moral commitment. "Much of this commitment stems from recognition of the need to view the patient as an autonomous human being, with rights and interests which are identifiable independently of medicine."⁸

New and rapidly changing medical technology is but one aspect of the climate of change occurring in biomedical law and ethics. Since 1980, we have come face to face with a twentieth century plague in the form of AIDS (acquired immunodeficiency syndrome). This perplexing, universally fatal disease gives rise to new issues and dilemmas, prompting us to re-examine our ideas about dying, about control over our bodies and over medical technology.

Medico-legal issues currently receive unprecedented media attention which began in the late 1970's and has steadily accelerated. The Quinlan case⁹ set the stage for current developments in medical decision-making for incompetent patients. Since then many such

⁷Englehardt, H. "Advance Directives and the Right to be Left Alone" in Hackler et al., infra note 50, at 42.

⁸McLean, S. Patient's Right to Know: Information, Disclosure, the Doctor and the Law 1989 Aldershot, Hants.: Gower, at 3.

⁹In Re Quinlan 355 A.2d 647 (N.J.S.C. 1976)

cases have come before the courts, predominantly, but not exclusively, in the United States. The Quinlan case was also the catalyst for living wills legislation in the U.S.

In Canada, the Rodriguez case¹⁰ invoked a flurry of media attention. In the United States, Dr. Jack Kevorkian's quest for legalization of physician-assisted suicide is the focus of controversial debate. All of this is part of one issue: the quest for individual patient autonomy in medical treatment decision-making. This trend is in keeping with a more pervasive societal trend toward individual rights and autonomy, a trend which has been accelerating since the human rights movements of the 1960's and, in Canada, implementation of the Canadian Charter of Rights and Freedoms¹¹ in 1982.

"Over himself, over his own body and mind, the individual is sovereign."¹² In this succinct statement, John Stuart Mill articulated the principle of individual autonomy. Immanuel Kant described autonomy as "the foundation of human dignity and the source of all morality."¹³ These philosophical underpinnings gave rise to today's western societal focus on personal autonomy, respect for privacy and individual rights. It is in this cultural context that the law with respect to medical treatment developed and evolved.

¹⁰Rodriguez v. B.C. (A.G.) [1993] 3 S.C.R. 519 (S.C.C.); (1993) 76 B.C.L.R. (2d) 145 (B.C.C.A.); [1993] B.C.W.L.D. 347 (B.C.S.C.)

¹¹Canadian Charter of Rights and Freedoms, Part I of the Constitution Act, 1982, being Schedule B of the Canada Act, 1982 (U.K.)

¹²Mill, J.S. "On Liberty" (1859) in Hutchins, R.M. (Ed.) Great Books of the Western World, Vol. 43 1988 Chicago: Encyclopaedia Britannica, at 271.

¹³Hill, T.E. Autonomy and Self-Respect 1991 Cambridge: Cambridge Univ. Press, at 43.

Uprooting a long history of medical authoritarianism, patient autonomy has transformed relationships between health care providers and patients into a focus upon mutuality, reciprocity and shared decision-making.¹⁴ Health care providers are legally and morally bound to respect, honour and facilitate patients' medical treatment choices, ensuring individual sovereignty over body and mind.¹⁵ This means that a competent patient has the right to decide which treatments he or she will accept or refuse. The ultimate decision-making authority resides with the patient.¹⁶

Informed consent goes hand in hand with patient autonomy, ensuring that patients, not health care providers, exert control over medical treatment decisions. Informed consent doctrine demands that consent to medical treatment be voluntary and informed and given by a mentally competent adult or mature minor.¹⁷ This means that the patient must have an understanding of the nature of the treatment and any associated risks and benefits.

He or she must have the legal capacity to give consent and such consent must be free of any element of coercion, deceit, duress, force or fraud.¹⁸ This does not preclude

¹⁴Roy, D.J., J.R. Williams and B.M. Dickens. Bioethics in Canada 1994 Scarborough: Prentice-Hall, at 111.

¹⁵Kennedy, I. Treat Me Right: Essays in Medical Ethics and Law 1988 Oxford: Clarendon, at 177.

¹⁶Katz, J. Duty and Caring in the Age of Informed Consent and Medical Science 1992 8 *Humane Medicine* 187, at 193.

¹⁷Brock, D.W. "Children's Competence for Health Care Decision-Making" in Kopelman, L.M. and J.C. Moskop (Eds.) Children and Health Care: Moral and Social Issues 1989 Dordrecht: Kluwer, at 189.

¹⁸Beauchamp, T.L. and J.F. Childress. Principles of Biomedical Ethics 1994 New York: Oxford Univ. Press, at 163.

idiosyncratic or seemingly irrational choices. The right of choice exists whether a patient's reasons for a particular decision are "rational, irrational, unknown or even non-existent."¹⁹ Health care providers who provide medical treatment without informed consent may be found legally liable for assault or battery.²⁰ The right of informed medical treatment refusal is a corollary to informed consent.²¹

Patient autonomy, and the correlative doctrine of informed consent, are well-established common law principles for competent or autonomous individuals, but what about rights of incompetent or non-autonomous individuals unable to provide treatment consent or refusal?²²

In Re Quinlan embodies the genesis of self-determination for non-autonomous patients. Since Quinlan, common law jurisdictions have honoured the principle of patient autonomy and the practice of proxy decision-making based on either substituted judgment or best interests standards for non-autonomous persons. This right is enshrined both statutorily and in case law. It is out of this regard for the rights of non-autonomous

¹⁹Sidaway v. Bethlem Hospital Governors [1985] 1 All E.R. 643, at 666.

²⁰Linden, A.M. Canadian Tort Law 1988 Toronto: Butterworths, at 43.

²¹In Re Conroy 486 A.2d 1209 (N.J.S.C. 1985), at 1222.

²²A preferable alternative to the terms competency/incompetency is autonomous/non-autonomous. An autonomous person is able to make treatment decisions while a non-autonomous person is unable to do so. (Weir, R.F. Abating Treatment with Critically Ill Patients 1989 New York: Oxford Press, at 69.)

patients that the concepts of proxy decision-making and advance health care directives have arisen.

Quinlan set the stage for many medical treatment decision-making issues specific to non-autonomous individuals which have since appeared before the courts and continue to be of relevance today:

- 1) Should the prior expressed wishes of previously competent persons with respect to medical treatment be followed?
- 2) What evidential burden should be satisfied in order to establish and verify prior expressed wishes of previously autonomous persons?
- 3) What approach should be taken in those cases where a previously autonomous person did not give expression to preferred treatment choices, and in cases of those persons who have never been autonomous?
- 4) Who has the authority to act as surrogate decision-maker in such cases, and what decision-making criteria should be followed?
- 5) Is there a legal distinction between withdrawing and withholding medical treatment?

- 6) Is there a legal distinction between "ordinary" and "extraordinary" medical treatment?

Other concepts germane to medical decision-making are beneficence, non-maleficence, and justice. Beneficence refers to the moral duty to help others and includes mercy, kindness and charity.²³ In a medical context, it involves doing that which promotes the patient's best interests. Non-maleficence refers to the non-infliction, prevention and removal of harm to others.²⁴ It is expressed in a maxim that is the foundation of medical ethics -- primum non nocere -- "above all, or first, do no harm."²⁵ The principle of justice requires distribution of societal resources in a manner that is fair and just to individuals and maximizes the benefit to society as a whole.²⁶

These principles may come into conflict. A medical treatment that is deemed to be in a patient's best interests may conflict with what the patient wants, causing a clash between autonomy and beneficence. Beneficence and non-maleficence may come into conflict when beneficial treatments cause harm at the same that they provide benefits. For instance, chemotherapy destroys cancerous cells but is also cytotoxic to normal cells, causing devastating effects.²⁷ Distributive justice involves choices that may conflict with

²³Beauchamp and Childress, supra note 18, at 260.

²⁴Ibid., at 190.

²⁵Ibid., at 189.

²⁶Ibid., at 327.

²⁷Rugo, H.S. "Cancer" in Tierney et al., supra note 3, at 65-70.

beneficence and non-maleficence. For instance, the limited availability of certain medical resources means that health care providers must deny treatment to some patients while providing it to others. The unavailability of treatment to the latter may violate beneficence and non-maleficence principles in that these patients will not receive treatment that is in their best interests and, as a result, may suffer harm. Justice may clash with autonomy. For example, if a patient's condition involves a poor prognosis, following his or her request for life-prolonging treatment may result in the denial of scarce resources, such as limited intensive care equipment, to another patient who could have been helped, thus resulting in injustice.²⁸

Such issues form the backdrop to the current emphasis on advance health care directives. Although the concept of advance directives is not new and, to date, only a small percentage of people have executed such documents²⁹, as public awareness increases, we are certain to see an increase in expression of medical treatment decisions through advance directives, creating novel issues for those who seek to implement these documents.

²⁸Gaul, A.L. Ethics of Clinical Judgment in Critical Care 1990 10(1) Crit. Care Nurse 24, at 26-27.

²⁹"One survey found that although 56% of adults discussed treatment preferences with family members, only 15% had filled out living wills. Others estimate that this number is as low as 9%." (Lerner, M.J. State Natural Death Acts: Illusory Protection of Individuals' Life-Sustaining Treatment Decisions 1992 29 Harvard J. Legis. 175, at 176.)

Chapter 2

Advance Health Care Directives: Origin, Meaning and Purpose

1) What Are Advance Health Care Directives?

"Just as I choose a ship to sail in or a house to live in, so I choose a death for my passage from life."

Seneca (4 B.C.-65 A.D.)

In keeping with informed consent, autonomy and self-determination precepts, a mechanism allowing competent individuals to give prior instructions regarding future medical treatments when they become non-autonomous, exists in the form of advance health care directives: instructional directives or living wills and durable powers of attorney for health care. This concept was first posited by Louis Kutner in 1969³⁰ but lay dormant until 1976 when two events transformed the fabric of North American biomedical law and ethics: 1) California enacted the first living wills statute, the "Natural Death Act," and 2) the New Jersey Supreme Court decided In Re Quinlan.³¹

Instructional directives allow individuals to specify medical treatment preferences. An instructional directive may consist of a pre-printed form, or it may be a simple handwritten document. It may be complex, anticipating a myriad of clinical states and

³⁰Kutner, L. Due Process of Euthanasia: the Living Will, a Proposal 1969 44 Ind. L.J. 539.

³¹Condie, C. Comparison of the Living Will Statutes of the Fifty States 1988 14 J. Contemp. Law 105, at 105.

treatment choices, or it may simply refer to a single treatment choice. Instructional directives are further sub-divided into: 1) Non-specific statements and 2) Scenario-and-treatment-specific statements.³²

Conceptually, instructional directives or living wills are rooted in trust law:

The living will is analogous to a revocable or conditional trust with the patient's body as the res, the patient as the beneficiary and grantor, and the doctor and hospital as the trustees. The doctor is given authority to act as the trustee of the patient's body by virtue of the patient's consent to treatment. He is obligated to exercise due care and is subject to liability for negligence. The patient is free at any time to revoke the trust.³³

Living wills differ from testamentary wills. Testamentary wills direct property disposition upon the will-maker's death. Living wills direct medical treatment decisions if and when the will-maker becomes decisionally incompetent.³⁴ Conrad advocates use of expressions such as "patient's choice" and "expression of medical treatment preferences," which connote choice and decision-making autonomy, rather than "living will," which suggests death and, therefore, may be confused with testamentary wills.³⁵

³²Emanuel, L. Advance Directives: What Have We Learned So Far? 1993 4 J. Clin. Ethics 8, at 8.

³³Kutner, supra note 30, at 552.

³⁴Francis, L.P. Evanescence of Living Wills 1988 14 J. Contemp. Law 27, at 27.

³⁵Conrad, A.F. Elder Choice 1993 19 Am. J. Law Med. 233, at 277.

Agency law forms the legal foundation of durable powers of attorney for health care. Durable powers of attorney for health care allow competent individuals to appoint agents or surrogates to act on their behalf with respect to medical treatment decisions in the event of future decisional incompetency. They differ from traditional powers of attorney which invest surrogates with decision-making authority regarding financial matters. Rather, durable powers of attorney for health care instruct and empower surrogates with medical decision-making authority.³⁶ Some jurisdictions have separate statutes governing instructional advance directives and durable powers of attorney for health care; whereas other jurisdictions include both types of directives under one statutory framework.³⁷

Durable powers of attorney for health care have been called "preventive medicine for difficult decisions."³⁸ These directives demonstrate greater flexibility than instructional directives. They can be used for all medical treatment decisions thus circumventing limitations intrinsic to early living wills statutes, such as "terminal condition" requirements.³⁹ Instructional and proxy directives complement each other. Ideally, the

³⁶Zinberg, J.M. Decisions for the Dying: an Empirical Study of Physicians' Responses to Advance Directives 1989 13 Vermont L. Rev. 445, at 451.

³⁷Juengst, E.T. and C.J. Weil. "Interpreting Proxy Directives: Clinical Decision-Making and the Durable Power of Attorney for Health Care" in Hackler et al., infra note 50, at 22.

³⁸Steinbrook, R. and B. Lo. Decision Making for Incompetent Patients by Designated Proxy: California's New Law 1984 310 N.E.J.M. 1598, at 1601.

³⁹Zinberg, supra note 36, at 460.

maker of an advance directive would execute both types -- a proxy directive designating a surrogate decision-maker and an instruction directive to guide the proxy.⁴⁰

Advance directives are about personal control, dignity and autonomy. People consider many factors when making decisions to forgo or accept treatment. In addition to the most prevalent factor, fear of intractable pain, a person may fear dependency, helplessness, loss of control and indignity,⁴¹ or a certain manner of dying, such as a "sensation of choking"⁴² or a "gruesome death."⁴³ It is a highly subjective, individualized judgement and one person may be prepared to tolerate a level of discomfort that another would not accept.

Inherent subjectivity and individuality precludes a standardized blueprint for a universal advance directive format. Standardized forms serve as mere guidelines to express core values and treatment goals specific to each individual and considerable variability in form and structure exists (Appendix B). Advance directives may consist of instructional directives, durable powers of attorney for health care or combinations of the

⁴⁰Singer, P.A. Advance Directives in Palliative Care 1994 10(3) J. Palliative Care 111, at 114.

⁴¹Pearlman, R.A., K.C. Cain, D.L. Patrick, D.L. et al. Insights Pertaining to Patients' Assessments of States Worse than Death 1993 4 J. Clin. Ethics. 33, at 35.

⁴²Rodriguez v. B.C. (A.G.): Excerpt from Proceedings at Chambers 1993 9 Iss. Law & Med. 303, at 307.

⁴³Ibid., at 306.

two and are fashioned in accordance with a specific jurisdiction's statute.⁴⁴ Directives may be clinically oriented -- focusing on condition specific treatment choices or therapeutic goals, or values oriented -- focusing on a person's beliefs, values system and world view.⁴⁵ Many health care facilities have formulated their own documents⁴⁶ and faith communities have developed their own formats in accordance with their religious tenets.⁴⁷ Two examples are advance directives developed by Catholic⁴⁸ and Jewish⁴⁹ religious bodies.

2) Advantages and Disadvantages of Advance Directives

Advance directives offer many benefits, to patients, their families and loved ones, and to health care providers. Advance directives serve as expressions of individual autonomy and freedom to choose medical treatment preferences.

⁴⁴Olick, R.S. Approximating Informed Consent and Fostering Communication: Anatomy of an Advance Directive 1991 2 J. Clin. Ethics 181, at 182.

⁴⁵Singer, supra note 40, at 114.

⁴⁶Hays, H. Development of a Prior Directive Form for Use in a Community General Hospital 1993 9 Humane Medicine 48, at 49.

⁴⁷Olick, supra note 44, at 183.

⁴⁸Catholic Health Association of Manitoba. Statement on Advance Directives 1993.

⁴⁹Dorff, E.N. "A Time to be Born and a Time to Die:" a Jewish Medical Directive for Health Care 1992 44(3) United Synagogue Review 20.

By providing assurance to families and significant others that their loved one's wishes are being carried out, instructional advance directives can alleviate stress, anxiety and guilt associated with trying to determine what the person would have wanted.⁵⁰

Advance directives are beneficial to health care providers, offering clarity with respect to individual treatment preferences, enhanced communication between patients and caregivers, confidence that treatment is in harmony with patient values and preferences, and relieving the pressure to provide unwarranted maximum medical interventions. The willingness on the part of health care providers to assist individuals in creating a directive and following the directive may serve to enhance the relationship between the parties. By granting civil and criminal immunity to health care providers relying in good faith on a patients' directives, advance directive legislation alleviates caregiver concerns about potential civil legal liability and defensive medicine.⁵¹

Advance directives benefit society as a whole by allowing the enhancement of individual autonomy, in keeping with democratic precepts. The recognition and implementation of advance directives fulfils societal goals of respect for autonomy, amelioration of suffering and promotion of dignity.⁵² Advance directives, if they are

⁵⁰Hackler, C., R. Moseley and D.E. Vawter (Eds.) Advance Directives in Medicine (1989) New York: Praeger, at 4-5.

⁵¹Ibid.

⁵²Downie, J. "Where There is a Will, There May be a Better Way:" Legislating Advance Directives 1991-92 12 Health Law in Canada 73, at 77.

followed, may minimize use of inappropriate, undesired medical technologies, thus helping to reduce escalating health care costs.⁵³

While advance directives confer undeniable benefits, there are also problems associated with their use. Advance directives may be especially problematic for sanctity of life proponents who hold the value of life to be intrinsic and absolute, and they regard the withholding and withdrawing of aggressive medical treatment in situations where the treatment is not futile as contrary to divine will in determining life's end.⁵⁴

Potential problems may arise where an individual desires inappropriate, expensive medical treatment and demands it in his or her advance directive.⁵⁵ If health care providers follow such a directive, they violate the principles of beneficence, non-maleficence and justice as such treatment may not be in the patient's best interests, may cause harm to the patient, and may result in the denial of scarce medical resources to another patient who could benefit from them.

An advance directive attempts to project into the future which medical technologies will be acceptable or unacceptable to the maker of the document.⁵⁶ Instructional advance

⁵³Hackler et al., supra note 50, at 5.

⁵⁴Ibid.

⁵⁵Kapp, M.B. Response to the Living Will Furor: Directives for Maximum Care 1982 72 Am. J. Med. 855, at 856.

⁵⁶Leflar, R.B. "Framework for the Legal Analysis of Advance Directives in Health Care" in Hackler et al., supra note 50, at 64.

directives written remotely in time may not address a patient's situation. New treatment options and prognoses unanticipated by patients at the time of advance directive execution, may result in directives that may not accurately reflect an individual's true wishes.⁵⁷ The person may have changed his or her mind between execution of the directives and the occurrence of events triggering implementation.⁵⁸ Nonetheless, one study suggests a high degree of stability in patients' treatment preferences over time.⁵⁹

Vague, imprecise language may subject people to undesired medical interventions. Expressions such as "extraordinary measures," "heroic measures," "life-sustaining," "meaningful quality of life" are subject to multiple interpretations.⁶⁰ On the other hand, too precise language may result in denial of desired interventions.⁶¹ With autonomous patients, informed consent to one type of intervention is never implied to apply to a different but similar intervention. This principle applies equally to non-autonomous

⁵⁷Downie, supra note 52, at 77.

⁵⁸Advance Directives Seminar Group, Centre for Bioethics, Univ. of Toronto. Advance Directives: Are They an Advance? 1992 146(2) C.M.A.J. 127, at 128.

⁵⁹Everhart, M.A. and R.A. Pearlman. Stability of Patient Preferences Regarding Life-Sustaining Treatments 1990 97 Chest 159, at 159.

⁶⁰Silverman, H.J., J.K. Vinicky and M.R. Gasner. Advance Directives: Implications for Critical Care 1992 20 Crit. Care Med. 1027, at 1029.

⁶¹Brett, A.S. Limitations of Listing Specific Medical Interventions in Advance Directives 1991 266 J.A.M.A. 825, at 826.

patients. Health care providers cannot presume that treatment requests or refusals for specific interventions are applicable to different but similar interventions.⁶²

Health care providers face further difficulties in clinical interpretation. Medical decisions are based on probabilities and uncertainties with respect to prognosis.⁶³ Therefore, decisions as to when to declare an illness "incurable" vary from one clinician to another.⁶⁴

Clinically oriented advance directives, delineating specific clinical conditions and medical interventions, may be quite restrictive, locking patients into specific clinical scenarios.⁶⁵ Scenario-and-treatment-specific statements risk being too narrow and limiting as it is impossible to anticipate every possible clinical situation and every possible treatment choice.

Patients' choices may be framed in implicit assumptions about expected medical conditions or outcomes. For example, successful cardio-pulmonary resuscitation outcome depends on many variables. A person who is unaware of this may execute an advance

⁶²Emanuel, L.L., M.J. Barry, E.J. Emanuel et al. Advance Directives: Can Patients' Stated Treatment Choices Be Used to Infer Unstated Choices? 1994 32 Med. Care 95, at 101-102.

⁶³Dubler, N.N. Commentary: Balancing Life and Death -- Proceed with Caution 1993 83 Am. J. Public Health 23, at 24.

⁶⁴Silverman et al. supra note 60, at 1029.

⁶⁵Olick, supra note 44, at 182.

directive stating "no cardio-pulmonary resuscitation (CPR) under any circumstances" when, in fact, she might experience a clinical condition with a high probability of successful resuscitation.⁶⁶ Similarly, a person who executes an advance directive directing "no mechanical ventilation" out of fear of long-term ventilator dependence may forgo short-term mechanical ventilation with high a probability of successful outcome. Thus, someone who fails to envision the actual clinical scenario triggering his or her directive may be subjected to unwanted medical treatment.

Values history directives arose out of concerns regarding the limitations of clinically-oriented treatment specific directives. They are less restrictive than treatment-specific directives, clarifying and removing ambiguity with respect to treatment goals and values.⁶⁷ This type of directive allows individuals to complete a series of questions related to personal values and goals -- for example, attitudes with respect to health and illness, relationships with family, friends and health care providers, religious beliefs and spirituality, independence, control, and autonomy.⁶⁸ A portrait of the individual emerges, enabling surrogate decision-makers to determine treatment goals and preferences.

⁶⁶Silverman et al., supra note 60, at 1029.

⁶⁷Doukas, D.J. and L.B. McCullough. Values History: Evaluation of the Patient's Values and Advance Directives 1991 32 J. Fam. Prac. 145, at 146.

⁶⁸Higgins, G.L. Discovering a Patient's Values for Advance Directives 1993 9 Humane Medicine 52, at 54.

Values oriented directives can be used alone or in conjunction with instructional directives.⁶⁹ Since documents with both broad value statements and specific treatment choices may conflict, health care providers may consequently face dilemmas trying to determine precisely what patients' true wishes are.⁷⁰

Patients' choices may be skewed or biased by the language of standardized advance directive documents or influenced by health care providers' biases, values and beliefs.⁷¹ These factors may result in execution of advance directives that are not reflective of patients' true desires.

Health care providers may either disregard advance directives or adhere too rigidly to them, disregarding competent patients' contemporaneously expressed choices. In one study of hypothetical treatment scenarios, 40% of respondent physicians indicated that they would provide a level of care different from what patients and families had actually requested (in person or by advance directive).⁷²

⁶⁹Lambert, P., J.M. Gibson and P. Nathanson. Values History: an Innovation in Surrogate Medical Decision-Making 1990 18 Law, Medicine & Health Care 202, at 210-211.

⁷⁰Emanuel, L. Health Care Directive: Learning How to Draft Advance Care Documents 1991 32 J.A.G.S. 1221, at 1222.

⁷¹Malloy, T.R., R.S. Wigton, J. Meeske et al. Influence of Treatment Descriptions on Advance Medical Directive Decisions 1992 40 J.A.G.S. 1255, at 1258-1259.

⁷²Alemayehu, E., D. W. Molloy, G.H. Guyatt et al. Variability in Physicians' Decisions on Caring for Chronically Ill Elderly Patients:" an International Study 1991 144 C.M.A.J. 1133, at 1138.

Health care providers may view patient compliance with statutory requirements as the only legally valid expression of an advance directive. They may be unaware of and, therefore, disregard common law recognition of patient treatment choices.⁷³ Legislation may thus undermine rather than enhance patient autonomy, particularly statutes with "terminal condition" restrictions⁷⁴ and constraints on medical treatment choices such as disqualification of artificial hydration and nutrition as refusable treatments.⁷⁵

Reluctance to execute advance directives stems from a number of reasons. Preparation of advance directives requires serious deliberation about life, death and mortality -- issues many people prefer not to think about. Alternatively, many consider advance directives unnecessary, preferring to rely on family members to make medical treatment decisions in the event of future incompetency.⁷⁶ Others fear advance directives will be used to deprive them of medical care,⁷⁷ or will prompt undertreatment or abandonment by health care professionals.⁷⁸

⁷³Hackler et al., supra note 50, at 6.

⁷⁴Heintz, L.L. Legislative Hazard: Keeping Patients Living, Against Their Wills 1988 14 J. Med. Ethics 82, at 83.

⁷⁵Lerner, supra note 29, at 198.

⁷⁶Menikoff, J.A., G.A. Sachs and M. Siegler. Beyond Advance Directives -- Health Care Surrogate Laws 1992 327 N.E.J.M. 1165, at 1165.

⁷⁷Dubler, supra note 63, at 24.

⁷⁸Menikoff et al. supra note 76, at 1165.

Some people fear that the use of advance directives will lead to more adversarial relationships between patients and health care providers, eroding their traditional fiduciary relationship. They fear that health care providers may pressure people to execute advance directives for health care cost containment reasons rather than to enhance their medical decision-making autonomy. For these reasons, health care providers may hesitate to initiate dialogue and develop advance directives with their patients.⁷⁹

3) Advantages and Disadvantages Specific to Proxy Directives

Durable powers of attorney for health care avoid certain difficulties encountered with instructional directives. Designation of surrogate decision-makers ensures access to contemporaneous medical information with respect to clinical condition and medical treatment alternatives, thus more closely approximating informed consent.⁸⁰ Durable powers of attorney for health care allow individuals freedom to choose someone who shares their values, beliefs and interests to make treatment choices on their behalf or someone who will respect the values, beliefs and interests of the individual making the directive.

⁷⁹Hackler et al., supra note 50, at 5-7.

⁸⁰Leflar, supra note 56, at 64.

Without such a document, it is next of kin, in concert with the health care providers, who typically act as surrogate decision-makers for incompetent patients.⁸¹ According to this medical custom, family members are in the best position to determine treatment for non-autonomous patients. This is not always true and there are situations where this practice creates dilemmas. Family members may feel uncomfortable with their decision-making role.⁸² There may be dysfunctional family dynamics,⁸³ or conflict among family members.⁸⁴ There may be no close family members available.⁸⁵ People may develop close relationships with non-family members, preferring to rely on them rather than family members for surrogate decision-making. People who choose non-traditional family structures and lifestyles fall into this category.⁸⁶ AIDS patients may prefer someone other than biological family members to make treatment decision choices for them.⁸⁷ In the New York case of Evans v. Bellevue Hospital, an AIDS patient executed

⁸¹Hamann, A.A. Family Surrogate Laws: Necessary Supplement to Living Wills and Durable Powers of Attorney 1993 38 Villanova L. Rev. 103, at 103.

⁸²Ibid., at 172.

⁸³Ibid., at 168.

⁸⁴Ibid., at 170.

⁸⁵Ibid., at 171.

⁸⁶Torielli, G.M. Protecting the Non-Traditional Couple in Times of Medical Crisis 1989 12 Harv. Women's L.J. 220, at 235-236.

⁸⁷Schlyter, C. AIDS and Aid-in-Dying: Impact of AIDS on the Debate Over Euthanasia, Assisted Suicide and Cessation of Treatment 1990 Thesis Master of Laws, Univ. of Toronto, at 175.

a durable power of attorney for health care appointing a non-family member as his surrogate decision-maker.⁸⁸

In Re Guardianship of Kowalski underscores these issues. Physically disabled and decisionally incompetent following a motor vehicle accident, Sharon Kowalski was the subject of an eight-year legal battle over medical decision-making authority between her parents and her intimate companion, Karen Thompson.⁸⁹ Execution of an advance directive by Ms. Kowalski prior to her incompetency might have averted this discord.⁹⁰

One way to solve such dilemmas is to re-define "family":

...to include those persons who are available and competent, have been involved with and concerned about the patient, are knowledgeable about the patient's values and preferences, and are willing to apply the patient's values to making the decision...[and] might well include persons not related to the patient and might exclude relatives.⁹¹

⁸⁸Evans v. Bellevue Hospital N.Y.L.J. , July 28, 1987 (N.Y. County Ct. July 27, 1987).

⁸⁹In Re Guardianship of Kowalski 382 N.W.2d 861 (Minn. Ct. App. 1986), cert. denied 106 S. Ct. 1467 (1986), petition for rev. denied, (Minn. App. 18, 1986) [Kowalski No. 1]; 392 N.W.2d 310 (Minn. Ct. App. 1986) [Kowalski No. 2]; 478 N.W.2d 790 (Minn. App. 1991), petition for rev. denied (Minn. App. Feb. 10, 1992 [Kowalski No. 3])

⁹⁰Camelli, M.N. Extending Family Benefits to Gay Men and Lesbian Women 1992 68 Chicago-Kent L. Rev., at 463.

⁹¹Stanley, J.M. (Ed.) Appleton International Conference: Developing Guidelines for Decisions to Forgo Life-Prolonging Medical Treatment 1992 (September, Supplement) 18 J. Med. Ethics 6-21, at 10.

Many living wills statutes contain "terminal illness" restrictions,⁹² limiting the scope and effectiveness of advance directives. Durable powers of attorney for health care are free of such constraints and are applicable in any situation which incapacitates the principal.⁹³

There are also disadvantages associated with proxy directives. Proxies may exert pressure or duress on the principal in execution of the document.⁹⁴ A surrogate may fail to implement the principal's wishes in a faithful manner or may act in a manner contrary to his best interests.⁹⁵ Surrogates may be unavailable when needed. This problem can be averted by appointment of more than one surrogate or, alternatively, a statutory list of proxy decision-makers.⁹⁶

4) Conclusion

Advance directives are in keeping with a societal trend toward increased personal autonomy and responsibility. Use of advance directives in clinical and legal practice is in an embryonic state and there is still much to learn and discover. While advance directives confer many benefits, there are also potential problems with their use.

⁹²Lerner, supra note 29, at 189.

⁹³Leflar, supra note 56, at 65.

⁹⁴Ibid., at 66.

⁹⁵Ibid., at 65.

⁹⁶Ibid.

Nevertheless, legal recognition of these documents is a positive step toward honouring personal autonomy and individual choice in medical treatment decisions. Advance directives empower people to determine medical treatment decisions at a time when they are unable to voice those choices. They enable us to "search for that person's 'voice' and allow it to 'speak' to the greatest extent possible."⁹⁷

PART B

ADVANCE DIRECTIVES LAW: A COMPARATIVE ANALYSIS

Chapter 3

Legal Status of Advance Directives in Canada

In Canada, the right of non-autonomous individuals to self-determination with respect to medical decision-making and treatment choices is enshrined in the common law, constitutional law and legislation. Until very recently, Canada had no advance directives legislation and no constitutional guarantee of the individual's right to make medical treatment choices. This status changed with constitutional recognition of the latter and the enactment of Canada's first health care directives statute.

⁹⁷Lambert et al., supra note 69, at 209.

Constitutional recognition of medical decision-making autonomy first occurred in Morgentaler I, in which the Ontario Court of Appeal described the right of self-determination with respect to medical treatment choices as a deeply rooted, fundamental part of "life, liberty and security of the person."⁹⁸ The Supreme Court of Canada further elaborated these rights in Morgentaler II⁹⁹ and, most recently, in Rodriguez.¹⁰⁰ In Malette v. Shulman,¹⁰¹ and Fleming v. Reid,¹⁰² the Ontario Court of Appeal confirmed the right of non-autonomous individuals to make medical treatment choices by means of advance directives.

In Malette, Dr. Shulman, the defendant physician, transfused the unconscious Mrs. Malette despite his knowledge of her prior written refusal, consisting of a card stating "No blood or blood products under any circumstances."¹⁰³ The court recognized Mrs. Malette's card as a valid medical treatment refusal directive and found Dr. Shulman liable in battery. The court held that it is up to the patient, not the physician, to decide which treatments shall be administered and which shall not and that a directive such as Mrs.

⁹⁸Morgentaler v. R. 22 D.L.R. (4th) 641 (Ont. C.A.), at 665 (Morgentaler I).

⁹⁹Morgentaler v. R. (1988) 44 D.L.R. (4th) 385 (S.C.C.)(Morgentaler II)

¹⁰⁰Rodriguez, *supra* note 10.

¹⁰¹Malette v. Shulman (1987), 63 O.R. (2d) 243, 43 C.C.L.T. 62 (H.C.); (1990) 67 D.L.R. (4th) 321 (Ont. C.A.)

¹⁰²Fleming v. Reid (1991) 82 D.L.R. (4th) 298 (Ont. C.A.)

¹⁰³Malette, *supra* note 101, at 323.

Malette's is legally binding even if the physician regards the patient's decision as unreasonable, medically unsound and contrary to the patient's best interests:

A competent adult is generally entitled to reject a specific treatment or all treatment, or to select an alternate form of treatment, even if the decision may entail risks as serious as death and may appear mistaken in the eyes of the medical profession or of the community. **Regardless of the doctor's opinion, it is the patient who has the final say on whether to undergo the treatment.**¹⁰⁴ (Emphasis added.)

Fleming v. Reid involved two psychiatric patients who were given anti-psychotic drugs despite their prior competently expressed refusal.¹⁰⁵ The court asserted that a constitutional right to make medical treatment choices by means of advance directives exists and that a failure to honour such directives violates both the liberty and security interests protected by s.7 of the Charter:

The common law right to bodily integrity and personal autonomy...forms an essential part of an individual's security of the person and must be included in the liberty interest protected by s.7.¹⁰⁶

¹⁰⁴Ibid., at 328.

¹⁰⁵Fleming, *supra* note 102, at 299.

¹⁰⁶Ibid., at 312.

The court concluded that common law and constitutional rights were co-extensive, both being founded on societal recognition of dignity and autonomy of the person.¹⁰⁷ The court also endorsed advance directives legislation.¹⁰⁸

Canadian advance directives legislation is in its infancy. Manitoba was the first province to enact legislation pertaining to both instructional and proxy directives.¹⁰⁹ Ontario¹¹⁰ has subsequently enacted similar legislation and Alberta has draft legislation that would enable people to execute both instructional and proxy directives.¹¹¹ British Columbia,¹¹² Quebec¹¹³ and Nova Scotia¹¹⁴ have legislation governing proxy decision-making.

¹⁰⁷Ibid.

¹⁰⁸Ibid., at 318.

¹⁰⁹Health Care Directives and Consequential Amendments Act S.M. 1992 c.33, C.C.S.M. c.H27

¹¹⁰Advocacy Act S.O. 1992, c.32; Consent and Capacity Statute Law Amendment Act S.O. 1992, c.26; Consent to Treatment Act S.O. 1992, c.31; Substitute Decisions Act S.O. 1992, c.30

¹¹¹Advance Directives Act (Bill 58) Second Session, 23rd. Legislature, Legislative Assembly of Alberta (1994)

¹¹²Health Care (Consent) and Care Facility (Admission) Act S.B.C. 1993, c.48

¹¹³Public Curator Act S.Q. 1989, c.54

¹¹⁴Medical Consent Act C.S.N.S. 1989, c.279

Newfoundland¹¹⁵ has legislation for proxy decision-making as well as a statutory proposal for instructional advance directives legislation.¹¹⁶ The Law Reform Commission of Saskatchewan recommends the implementation of advance directives legislation.¹¹⁷ However, the actual resulting legislation may differ from such proposals as governments do not have to follow the recommendations of law reform commissions.

The Manitoba Act recognizes the right of every competent person to consent, refuse to consent or withdraw consent to his or her health care.¹¹⁸ Directives can be specific or general and are not limited to terminal patients. A directive can be permanent or temporary, taking into account periods of lucidity in otherwise incompetent patients.¹¹⁹

The Manitoba Act stipulates that instructional advance directives must be in writing, signed, witnessed and dated.¹²⁰ Although the Act provides examples of advance directives, no standardized form is mandated. All that is required is written

¹¹⁵Enduring Power of Attorney Act S.N. 1990, c.15

¹¹⁶Newfoundland Law Reform Commission. Discussion Paper on Advance Health Care Directives and Attorneys for Health Care 1992 NLRC-WP6

¹¹⁷Law Reform Commission of Saskatchewan. Proposals for an Advance Health Care Directives Act 1991

¹¹⁸Health Care Directives and Consequential Amendments Act, supra note 109, ss. 1, 2.

¹¹⁹Ibid., s.6(2).

¹²⁰Ibid., s.8.

documentation of one's medical treatment choices. The Act allows anyone aged sixteen and over to execute instructional advance directives.¹²¹ However, proxy decision-makers must be eighteen years of age or over.¹²²

Revocation must be executed in the same manner as a testamentary document in accordance with the Wills Act¹²³ -- by a later will, a later writing declaring an intention to revoke, or by burning, tearing or otherwise destroying the will with the intention of revoking it.¹²⁴

The Manitoba statute does not impose an onus of inquiry on health care providers but rather imposes an onus on those who execute advance directives to inform health care providers of their existence or revocation.¹²⁵ Manitoba grants immunity from prosecution or civil suit to health care providers who fail to follow an advance directive because they were unaware of its existence.¹²⁶ There is no penalty clause with respect to non-compliance where health care providers have knowledge of the existence of an advance directive. The remedy for non-compliance lies in the common law tort of battery.

¹²¹Ibid., s.4.

¹²²Ibid., s.12.

¹²³Wills Act, R.S.M. 1988, c. W150, s.16.

¹²⁴Health Care Directives and Consequential Amendments Act, supra note 109, s.9.

¹²⁵Ibid., s.21.

¹²⁶Ibid., s. 22.

Ontario's statutory framework is complex, consisting of four pieces of legislation.¹²⁷ The Consent to Treatment Act states that no treatment is to be administered to a non-autonomous person where there is evidence of a prior expressed treatment refusal.¹²⁸ Unlike Manitoba, in Ontario, a 16-year-old can act as a proxy.¹²⁹ The statute does not differentiate between written and oral advance directives and does not delineate the requirements for written instructional advance directives. Proxy directives are addressed in both the Consent to Treatment Act and the Substitute Decisions Act.¹³⁰

In conclusion, while the issue was being examined by a number of provinces, Malette and Fleming provided a further impetus to Canadian advance directives legislation. While Quebec and Nova Scotia had enacted legislation on proxy directives prior to these decisions, no province had legislation regarding instructional directives until Manitoba's Health Care Directives and Consequential Amendments Act was enacted in 1993. Ontario has since followed Manitoba's lead and this trend is likely to continue in other provinces.

¹²⁷Advocacy Act, Consent and Capacity Statute Law Amendment Act, Consent to Treatment Act, Substitute Decisions Act, supra note 110.

¹²⁸Consent to Treatment Act, supra note 110, s.24.

¹²⁹Ibid., s.17.

¹³⁰Consent to Treatment Act and Substitute Decisions Act, supra note 110.

Chapter 4

Legal Status of Advance Directives in Four Other Common Law Jurisdictions

1) United States

California enacted the first American living wills statute in 1976. Today all states and the District of Columbia legally recognize advance directives -- instructional, proxy, or both -- as evidence of patients' treatment choices.¹³¹

Living wills statutes enable people to create valid and legally enforceable living wills in accordance with specified procedural requirements. The Natural Death Act, Medical Treatment Decisions Act, Life-Prolonging Procedures Act and Life-Sustaining Procedures Act are among various titles ascribed to these statutes.¹³² Characteristics shared by all American living wills statutes include:

- execution formalities
- revocation requirements
- penalties for forgery or intentional destruction
- statements indicating that compliance with advance directives does not equate to suicide or assisted suicide
- civil and criminal immunity to health care providers who adhere to people's advance directives

¹³¹Singer, supra note 40, at 111.

¹³²Condie, supra note 31, at 107.

- "conscience clauses" and transfer provisions for health care providers who do not wish to follow directives.¹³³

Most jurisdictions require living wills to be executed in writing, signed, dated and witnessed by two adults.¹³⁴ Only four states (Florida, Louisiana, Texas and Virginia) have specific provisions for oral advance directives.¹³⁵ Louisiana's statute, based on Roman civil law, states that "a declaration may be made in writing, orally, or by other means of nonverbal communication."¹³⁶

All states and the District of Columbia have durable power of attorney legislation.¹³⁷ Many have dual legislation, with one statute governing instructional directives and a separate statute regulating proxy decision-making. More recent legislation contains instructional and proxy directives within the same statute. In some states, general power of attorney statutes can be interpreted to include health care decision-making.¹³⁸

¹³³Marzen, T.J. Medical Decisionmaking for the Incompetent Person: a Comprehensive Approach 1986 4 Issues in Law & Medicine 293, at 297.

¹³⁴Condie, supra note 31, at 113.

¹³⁵Ibid.

¹³⁶Ibid.

¹³⁷Doukas and McCullough, supra note 67, at 146.

¹³⁸Obade, C.C. Advance Healthcare Planning Under the New Federal Patient Self-Determination Act 1992 38 Prac. Law. 83, at 98.

Three states (Arkansas, Louisiana, and New Mexico) permit adults to make living wills for their minor children.¹³⁹ All other jurisdictions limit advance directives to adults. Adolescents' advance directives are not legally binding in any jurisdiction but offer persuasive evidence of patient wishes.¹⁴⁰

Many statutes suffer from "terminological vagueness" with respect to the language descriptive of medical conditions or medical technologies. Phrases such as "terminally ill," "heroic measures," and "life-prolonging procedures" are subject to multiple interpretations.¹⁴¹ Subjectivity in interpretation leads to uncertainty and poses difficulties for health care providers in implementing advance directives. Faced with uncertainty, health care providers may refuse to follow such directives, negating individual autonomy and control over health care decision-making.¹⁴²

Most statutes have a "terminal condition" requirement.¹⁴³ Terminal illness restrictions are problematic for a number of reasons. First, terminal illness restrictions

¹³⁹Cahill, J. (Ed.) Nurse's Handbook of Law and Ethics 1992 Springhouse, Pa.: Springhouse, at 176.

¹⁴⁰Rushton, C.H. and M.E. Lynch. Dealing With Advance Directives for Critically Ill Adolescents 1992 12(6) Crit. Care Nurse 31, at 36.

¹⁴¹Keyserlingk, E.W. Second-Generation Advance Directives: Will Reforming the Law Improve the Practice? 1993 9 Humane Medicine 57, at 58-59.

¹⁴²Nanovic, S.J. Living Will: Preservation of the Right-to-Die Demands Clarity and Consistency 1990 95 Dickinson L. Rev. 209.

¹⁴³Condie, supra note 31, at 111-112.

focus on the "timing of death rather than on the futility and the burden of treatment to the patient."¹⁴⁴ Secondly, terminal illness restrictions exclude individuals with non-terminal, chronic or irreversible medical conditions, severely limiting the protection offered by advance directives.¹⁴⁵ Thirdly, while an illness may be terminal, death may not occur for a number of years after onset and initial diagnosis.¹⁴⁶ For example, AIDS is known to be universally fatal but there is an incubation period of 8-11 years between diagnosis of HIV infection and development of full-blown AIDS resulting in death.¹⁴⁷ Some states define a "terminal illness" as one in which death is "imminent."¹⁴⁸ In these jurisdictions, an AIDS patient would have to wait until a few months before death is anticipated in order to execute an advance directive.¹⁴⁹ By that time, he may be precluded from executing an advance directive due to AIDS-related dementia which affects up to 75% of AIDS patients,¹⁵⁰ causing cognitive dysfunction and decisional incompetency.¹⁵¹

¹⁴⁴Lerner, supra note 29, at 196.

¹⁴⁵Francis, supra note 34, at 37-38.

¹⁴⁶Condie, supra note 31, at 111-112.

¹⁴⁷Grohmann, S.M. and K.B. MacDonell. Predicting the Course of HIV Infection 1992 26(1) Medical Aspects of Human Sexuality 22, at 22.

¹⁴⁸Lerner, supra note 29, at 191.

¹⁴⁹Ibid., at 186-195.

¹⁵⁰Adams, T. HIV-Related Dementia 1988 94(2)(Jan. 20) Nursing Times 45, at 45.

¹⁵¹McArthur, J.C. Neurologic Manifestations of AIDS 1987 66 Medicine 407, at 410-411.

Many statutes specifically exclude refusal of artificial hydration and nutrition.¹⁵² This exclusion has its roots in the historical debate as to whether hydration and nutrition therapies constitute basic, routine comfort care measures or medical treatment.¹⁵³

Only a handful of jurisdictions recognize another state's legislation.¹⁵⁴ A problem thus arises when a person executes an advance directive in one jurisdiction and the triggering event occurs in another. The enactment of advance directives legislation in other common law jurisdictions, such as Canada and Australia, makes this an opportune time to introduce reciprocity statutes, ensuring that a patient's wishes are respected in the event that the individual requires medical care outside the jurisdiction where the directive was signed. This type of arrangement is in effect in other areas of the law, such as family law where jurisdictions honour one another's child support statutes to ensure that rights are not lost simply because one party leaves the jurisdiction.¹⁵⁵ Similar arrangements in the area of patients' treatment rights, both on an inter-state and international level, would enhance medical decision-making autonomy.

Overly rigorous statutory standards produce formidable obstacles to the realization of patient treatment choices and the exercise of patient autonomy. These statutory initiatives have been heavily criticized by health care professionals, lawyers and

¹⁵²Francis, *supra* note 34, at 33-34.

¹⁵³Lerner, *supra* note 29, at 203.

¹⁵⁴Condie, *supra* note 31, at 114.

¹⁵⁵Reciprocal Enforcement of Maintenance Orders Act R.S.M. 1987, c. M20.

bioethicists. The recent passage of family surrogate statutes has been one response to deficiencies in American advance directives legislation. These statutes have codified the medical practice of allowing family members to make medical treatment decisions for non-autonomous persons in the absence of advance directives documents.¹⁵⁶

Statutory amendments precipitated by the U.S. Supreme Court Cruzan decision have broadened the criteria to include individuals such as PVS patients and to permit the refusal of artificial nutrition and hydration.¹⁵⁷ Cruzan involved a parental petition for removal of a feeding from a PVS patient in accordance with her prior expressed wishes. The U.S.S.C. held that a non-autonomous person has a constitutionally protected liberty interest in refusing medical care and gave the states the authority to determine the validity of the person's previously expressed wishes.¹⁵⁸

Another facet of patient autonomy is reflected by the federal Patient Self-Determination Act (PSDA),¹⁵⁹ enacted in 1990 with the objective of enhancing awareness of patients' rights and fostering planned health care decision-making by enhancing

¹⁵⁶Hamann, supra note 81, at 131-132.

¹⁵⁷Meisel, A. Retrospective on Cruzan 1992 20 Law, Medicine & Health Care 340, at 344-345.

¹⁵⁸Cruzan v. Director, Missouri Department of Health 110 S.Ct. 2841 (1990) (U.S.S.C.), at 2851-2852.

¹⁵⁹Omnibus Budget Reconciliation Act of 1990 Public Law No. 101-508 Para. 4206, 4751 (codified in scattered sections of 42 U.S.C., especially Para. 1395cc, 1396A (West Supp. 1991)

opportunities to execute advance directives.¹⁶⁰ The Act mandates that all federally funded health care facilities (including hospitals, health maintenance organizations, hospices, personal care homes, and home health care agencies):

- 1) provide written information regarding state laws on medical decision-making, including treatment refusal rights and the right to execute advance directives;
- 2) document in patients' medical records the presence of advance directives;
- 3) provide educational programs to staff and community members regarding state laws governing advance directives;
- 4) maintain written institutional policies and procedures on advance directives.¹⁶¹

¹⁶⁰Olick, supra note 44, at 181-182.

¹⁶¹American Bar Association Commission on Legal Problems of the Elderly. Patient Self-Determination Act: State Law Guide 1991 (August), at 1.

While the PSDA recognizes the legal validity of oral directives, the Act expressly defines an advance directive as a written instruction and strongly urges the use of this format.¹⁶²

One of the PSDA's underlying premises is that patients will execute advance directives if they are given appropriate information, knowledge and encouragement.¹⁶³ In fact, few people report lack of information as the reason for not completing an advance directive.¹⁶⁴ Rather, they report difficulties with the mechanics of execution, problems such as finding witnesses and notaries, and limited experience with legal documents as disincentives to preparing advance directives. Most legislation imposes complex requirements, requiring the drafter to be articulate and have experience with legal documents,¹⁶⁵ and it is not surprising that most people who have completed advance directives are well-educated. One study indicates completion rates of 21% for people with less than high school education, compared with 34% for those with high school education and 50% for those with college education.¹⁶⁶ As a result, the complexity of most American advance directives legislation presents considerable barriers to less advantaged Americans.

¹⁶²Ibid., at 19.

¹⁶³La Puma, J., D. Orentlicher and R.J. Moss. Advance Directives on Admission: Clinical Implications and Analysis of the Patient Self-Determination Act of 1990 1991 266 J.A.M.A. 402, at 403.

¹⁶⁴High, D.M. Advance Directives and the Elderly: a Study of Intervention Strategies to Increase Use 1993 33 Gerontologist 342, at 347.

¹⁶⁵Ibid., at 348.

¹⁶⁶Ibid., at 346.

Another barrier is lack of physician initiative in discussing advance directives with patients.¹⁶⁷ Physicians are reluctant to approach the subject because of their own discomfort with the topic and the belief that patients will raise the issue if it is important to them.¹⁶⁸ But most patients expect physicians to initiate advance directive discussions,¹⁶⁹ and perceive lack of physician initiative as a barrier to communication.¹⁷⁰ Patient reluctance to initiate such discussion may be ascribed to overcoming traditionally passive roles engendered by a legacy of medical authoritarianism.¹⁷¹

In conclusion, American advance directive laws contain numerous deficiencies. Vague, ambiguous terminology may make interpretation difficult. Restrictions imposed, both with respect to medical conditions and treatments, serve to preclude many individuals who may wish to, from executing a living will. Limited inter-jurisdictional reciprocity means that an advance directive made in one state will not necessarily be honoured in another, thus restricting rather than enhancing patient autonomy.

¹⁶⁷Haas, J.S., J.S. Weissman, P.D. Cleary et al. Discussion of Preferences for Life-Sustaining Care by Persons with AIDS: Predictors of Failure in Patient-Physician Communication 1993 153 Arch. Intern. Med. 1241, at 1247.

¹⁶⁸La Puma et al., supra note 163, at 402-403.

¹⁶⁹Stelter, K.L., B.A. Elliott and C.A. Bruno. Living Will Completion in Older Adults 1992 152 Arch. Intern. Med. 954, at 957.

¹⁷⁰Emanuel, L.L., M.J. Barry, J.D. Stoeckle, J.D. et al. Advance Directives for Medical Care: the Case for Greater Use 1991 324 N.E.J.M. 889, at 889.

¹⁷¹Loewy, E.H. Furthering the Dialogue on Advance Directives and the Patient Self-Determination Act 1994 3 Cambridge Q. of Healthcare Ethics 405, at 405-406.

2) Great Britain

Great Britain has no advance directives legislation and no constitutional guarantees regarding medical decision-making such as provided by s. 7 of Canada's Charter of Rights and Freedoms.¹⁷² Recent English case law with respect to medical decision-making rights of non-autonomous individuals endorses advance directives.

Lord Butler-Sloss, speaking for the Court of Appeal, approved Canada's Malette case in Re: T.,¹⁷³ and, in Bland, stated:

...the right to reject treatment extends to deciding not to accept treatment in the future by way of an advance directive or "living will."¹⁷⁴

The English Law Commission recommends implementation of advance directives legislation to provide clarity and guidance for patients and health care providers.¹⁷⁵ In its proposed statutory framework, the Commission endorses Malette¹⁷⁶ as well as Canadian statutes and statutory proposals.¹⁷⁷

¹⁷²Stern, K. Living Wills in English Law 1993 7 Palliative Med. 283, at 283.

¹⁷³Re T. [1992] 4 All E.R. 649, at 668.

¹⁷⁴Bland, supra note 2, at 342, per Butler-Sloss, L.J., at C.A. level.

¹⁷⁵English Law Commission. Mentally Incapacitated Adults and Decision-Making: Medical Treatment and Research 1993 (Consultation Paper No. 129), at 27.

¹⁷⁶Ibid.

¹⁷⁷Ibid., at 31-46.

Scotland's Law Commission is not eager to embrace advance directives legislation. The Commission commends the American model but states that this type of legislation is unnecessary in Scotland due to differences in both the two countries' health care systems and socio-political climates.¹⁷⁸ The Scottish legal system also differs in that it is based on Roman civil law rather than English common law.

3) Australia

Australia was quick to respond to American legislation with the enactment of advance directives legislation in Southern Australia,¹⁷⁹ the Northern Territory,¹⁸⁰ Victoria,¹⁸¹ and the Capital Territory.¹⁸² Western Australia and Tasmania are considering enacting legislation based on the Victorian model.¹⁸³

The Capital Territory statute has provisions for proxy decision-making only. The two Australian Natural Death Act statutes are patterned after California's Natural Death

¹⁷⁸Scottish Law Commission. Mentally Disabled Adults: Legal Arrangements for Managing Their Welfare and Finances 1991 (Discussion Paper No. 94), at 312.

¹⁷⁹Natural Death Act 1983 (S.A.)

¹⁸⁰Natural Death Act 1988 (N.T.)

¹⁸¹Medical Treatment Act 1988 (Vic.), as amended by Medical Treatment (Enduring Power of Attorney) act 1990 (Vic.) and Medical Treatment (Agents) Act 1992 (Vic.)

¹⁸²Powers of Attorney (Amendment) Act 1989 (Capital Terr.)

¹⁸³Law Reform Commission of Western Australia. Discussion Paper on Medical Treatment for the Dying 1988 (Project No. 84), at 32-36.

Act, and they contain most of the features typical of early American living wills statutes.¹⁸⁴ They are also subject to the same limitations and narrow scope. Victoria's Medical Treatment Act (MTA) is broader and more flexible, allowing any medical treatment to be withheld from a person who has clearly expressed a treatment refusal decision, either generally or of a particular kind by means of a treatment refusal certificate.¹⁸⁵

These statutes are regulatory and protective in nature with two objectives: 1) to regulate procedures enabling terminally ill patients to direct the discontinuation of "extraordinary" life-sustaining medical treatment; and 2) to provide immunity from civil and criminal liability for doctors who comply with valid directives.¹⁸⁶ Neither statute permits a general refusal of treatment and both contain "terminal illness" and "extraordinary measures" restrictions.¹⁸⁷ These restrictions reflect the diagnosis, prognosis and treatment configuration predominant in early American living wills legislation and are subject to the same problems.

¹⁸⁴Lanham, D. and B. Fehlberg. Living Wills and the Right to Die with Dignity 1991 18 M.U.L.R. 329, at 337.

¹⁸⁵Medical Treatment Act, *supra* note 181, s.5.

¹⁸⁶Mendelson, D. Medico-Legal Aspects of the "Right to Die" Legislation in Australia 1993 19 M.U.L.R. 112, at 115-116.

¹⁸⁷Lanham and Fehlberg, *supra* note 184, at 337.

Both statutes require written directives, have a minimum age limit of 18 years and require the presence of two witnesses.¹⁸⁸ South Australia's statute imposes no requirements as to who may act as a witness, whereas the Northern Territory statute requires two witnesses who must be 18 or over and neither must be a medical practitioner involved in the person's treatment.¹⁸⁹ Southern Australia requires compliance with a prescribed form.¹⁹⁰

Both statutes provide immunity from criminal and civil liability for health care providers who follow advance directives made in accordance with the statutory provisions, but neither has sanctions against medical practitioners for deliberate non-compliance.¹⁹¹

Victoria's Medical Treatment Act addresses some of the problems found in the South Australian and Northern Territory statutes. The MTA has two primary objectives: 1) to establish procedures for medical treatment refusal, and 2) to penalize medical practitioners for non-compliance with a valid treatment refusal certificate.¹⁹² It sets out

¹⁸⁸Ibid., at 330.

¹⁸⁹Natural Death Act (N.T.), supra note 180, s.4(2).

¹⁹⁰Natural Death Act (S.A.), supra note 179, s.4(1).

¹⁹¹Lanham and Fehlberg, supra note 184, at 349.

¹⁹²Mendelson, supra note 186, at 123.

formal requirements and procedures for execution of a treatment refusal certificate and creates a statutory offence of medical trespass.¹⁹³

As is the case with the two Natural Death Act statutes, the MTA requires a person to be at least 18 years of age and of sound mind in order to execute a certificate of treatment refusal.¹⁹⁴ For purposes of the MTA and the Natural Death Acts, the definition of "sound mind" is identical to that required for the execution of testamentary wills (that the person must be capable of understanding the nature and consequences of his actions). This does not necessarily exclude a person with mental illness.¹⁹⁵

Treatment refusals must be voluntary and clearly expressed "in writing, orally, or in any other way in which the person can communicate."¹⁹⁶ The certificate must be signed by two witnesses, one of whom must be a medical practitioner. Witnesses must be satisfied that the individual understands the nature of his medical condition and that his refusal is voluntary.¹⁹⁷

Both Natural Death Acts have provisions that allow medical practitioners to override a patient's directive on the grounds that the patient may not have understood the

¹⁹³Medical Treatment Act, supra note 181, s.6.

¹⁹⁴Ibid., s.5.

¹⁹⁵Mendelson, supra note 186, at 116-117.

¹⁹⁶Medical Treatment Act, supra note 181, s.5(3).

¹⁹⁷Ibid., s. 5(1).

nature and consequences of his actions when he made the directive.¹⁹⁸ The MTA has no such override provision. Once presented with a treatment refusal certificate in compliance with the Act, a medical practitioner is statutorily bound to honour it.¹⁹⁹

Unlike the other two statutes, the MTA has no "terminal illness" or "extraordinary measures" restrictions. Under the MTA, a person is free to refuse medical treatment "generally or specifically" -- including treatment for treatable and/or curable conditions but the Act does have a "current condition" requirement, clearly stipulating that treatment refusal certificates are not applicable if a patient's medical condition changes to such an extent that the condition in relation to which the certificate was made is no longer current.²⁰⁰ This requirement impedes medical decision-making autonomy because it excludes the possibility of utilizing treatment refusal certificates for decision-making related to future medical conditions.

Victoria's statute provides for the appointment of surrogate decision-makers.²⁰¹ Agents are prohibited from refusing treatment which is appropriate and proportionate, and surrogate decision-making powers are restricted to situations in which medical treatment would cause "unreasonable distress" or where there are reasonable grounds for believing

¹⁹⁸Lanham and Fehlberg, supra note 184, at 346.

¹⁹⁹Mendelson, supra note 186, at 130.

²⁰⁰Medical Treatment Act, supra note 181, s.7(3).

²⁰¹Medical Treatment (Enduring Power of Attorney) Act 1990 (Vic.)

that the patient, if competent, would consider the treatment unwarranted.²⁰² "Unreasonable distress" is construed in a subjective sense to mean a treatment that would cause distress to a particular individual.²⁰³ Surrogate decision-makers are not constrained by "terminal illness" restrictions and have the power to refuse treatment for permanently unconscious or persistent vegetative state (PVS) patients as well as for temporarily incompetent patients with treatable and/or curable illnesses.²⁰⁴

Physician non-compliance with treatment refusal certificates executed in accordance with the MTA constitutes a criminal offence.²⁰⁵ Because this is a summary offence, the Medical Board is not required to deny registration to a medical practitioner convicted under the MTA or to institute disciplinary proceedings for professional misconduct.²⁰⁶

Western Australia's Law Reform Commission recommends the MTA as a model statute but suggests: 1) immunity from criminal prosecution or civil liability to physicians who administer analgesic medication even where these drugs may have the effect of

²⁰²Ibid., s.5B(2).

²⁰³Lanham, D. and S. Woodford. Refusal by Agents of Life-Sustaining Medical Treatment 1992 18 M.U.L.R. 659, at 670.

²⁰⁴Mendelson, supra note 186, at 137.

²⁰⁵Ibid., at 146.

²⁰⁶Ibid.

shortening the patient's lifespan; and 2) removal of the distinction between palliative care and other forms of medical treatment, so that patients could refuse both.²⁰⁷

4) New Zealand

While New Zealand has no specific advance directives legislation, the Bill of Rights Act provides that "everyone has the right to refuse to undergo any medical treatment."²⁰⁸ This is a very broad right, with no restrictions as to diagnosis, prognosis or type of treatment. The statute does not specifically address whether or not that right can be expressed in an advance directive. Based on the persuasive nature of the jurisprudence in other common law jurisdictions, specifically the constitutional recognition of the right to exercise medical treatment choices by means of advance directives in the United States and Canada, a compelling argument can be put forth that such a right exists in New Zealand.

In conclusion, England is in the process of developing advance directives legislation, based on Canadian, American, and Australian models. Australia's advance directives movement is due to enter another phase. While New Zealand's Bill of Rights Act contains medical treatment refusal rights, legal scholar Rosemary Tobin submits that this is not enough:

²⁰⁷Law Reform Commission of Western Australia, supra note 183, at 32-36.

²⁰⁸New Zealand Bill of Rights Act 1990, s.11.

...legislative recognition [of advance directives] in New Zealand would alleviate some of the undoubted concerns of doctors faced with the prospect of discontinuing treatment...to an incompetent patient...[and] would also alleviate concerns of those who do not wish to be kept alive indefinitely in a non-sentient vegetative state, and who wish to have some say in the matter.²⁰⁹

Thus, all common law jurisdictions embrace advance directives as an important element in promoting, enhancing and ensuring patient autonomy. Scotland and two North American jurisdictions, Quebec and Louisiana, adhere to the civil legal system. With the exception of Scotland, these jurisdictions endorse and have, in fact, enacted advance directives legislation. Other non common law jurisdictions, such as Denmark and the Netherlands, are also considering legal recognition of advance directives.²¹⁰

²⁰⁹Tobin, R. Incompetent Patient's Right to Die: Time for Legislation Allowing Advance Directives? 1993 N.Z. Recent L. Rev. 103, at 119.

²¹⁰Singer, supra note 40, at 111.

PART C

RELEVANCE AND IMPLICATIONS OF ADVANCE HEALTH CARE DIRECTIVES

Chapter 5 - Perceptions, Attitudes and Opinions of Medical and Legal Professionals

1) Introduction

The introduction and implementation of advance directives in clinical settings will present unique issues and challenges to health care professionals. Their perceptions, attitudes and opinions are explored and compared to those of emergency medical services personnel and lawyers for the purpose of determining their knowledge base and understanding of the legal status of advance directives and potential problems and issues in their clinical application.

2) Hypothesis

Through empirical analysis, I will explore and analyze:

1. The differences, if any, between health care professionals, emergency medical services personnel and lawyers in perceptions, attitudes and opinions regarding the legal status of advance directives and their implementation.

2. Issues and potential problems that may arise for health care professionals, emergency medical services personnel and lawyers as a result of advance health care directives legislation.

3) Comparison to Other Studies

Other studies have explored attitudes, opinions and perceptions of the general public, patient groups, and health care providers. The health care provider studies focus predominantly on physician attitudes. There are two studies dealing with nurses' opinions. This study is not confined to physicians and nurses but includes other health care professionals, in keeping with the multi-disciplinary nature of the health care team and expanding roles for health care providers.

4) Methodology

I conducted a survey of Manitoba health care professionals (hereinafter referred to as HCPs), emergency medical services personnel (hereinafter referred to as EMSP) and lawyers to determine their knowledge and understanding of advance directives; their perceptions, attitudes and opinions on the implementation of advance directives; experiences they have had in this area and the impact of these experiences on their practice.

5) Format

Questionnaires were distributed to a cross-section of the above-mentioned groups.²¹¹ All groups received quantitative questionnaires. A total of 300 surveys were distributed to HCPs. Of these, 243 responded, for a response rate of 84%. Of these, 30 were also given an additional questionnaire, asking them to provide definitions of terms relevant to advance directives. Twenty-seven or 90% completed this survey component. A total of 40 surveys were distributed to EMSP. Of these, 31 responded, for a response rate of 78%. A total of 30 lawyers were surveyed. Of these 21 responded, for a response rate of 70%.

The HCP group was comprised of 152 nurses, 39 physicians, 25 hospital pharmacists and 27 "other" health care providers. The "other" category consisted of 11 registered technologists (7 respiratory therapists, 3 laboratory technologists and 1 biomedical technologist), 5 health care aides, 4 social workers, 3 occupational therapists, 1 physiotherapist, 1 dietician and 2 respondents who did not identify their specialty.

The quantitative questionnaires were designed to address various health care decision-making situations, factors that lead to decisional incompetency, and a variety of medical technologies. The quantitative approach asked for "Yes-No" responses. However, respondents were invited to add additional comments if they wished. During the

²¹¹The questionnaires are reproduced in Appendix C.

interviews, I actively sought reasons and explanations for a particular choice, as well as allowed for open-ended discussion and dialogue.

The survey questions were broken down into two basic categories, consisting of:

- 1) questions regarding respondents' general knowledge base and understanding of:
 - a) medical technology
 - b) the legal status of advance health care directives
 - c) relevant bioethical concepts:
 - i) patient autonomy
 - ii) decisional competency
 - iii) resource allocation
- 2) questions with specific hypothetical health care treatment decision-making scenarios, dealing with the following areas:
 - a. vague v. specific wording
 - b. withholding v. withdrawing treatment
 - c. high technology v. low technology d. acute v. chronic illness
 - e. "irrational" treatment choices
 - f. psychiatric treatment issues
 - g. euthanasia

The questions were grouped and analyzed according to these categories or themes. Questions pertaining to the same theme do not necessarily occur in sequence in the questionnaires. This structuring is deliberate to avoid clustering of similar themes.²¹²

The qualitative analysis consists of three components:

- 1) Respondents' reasons for stating that a particular treatment, tube feeding, could be either a medical treatment or a comfort care measure.
- 2) Respondents' definitions of seven terms relevant to advance directives.²¹³
- 3) The contents of respondents' actual or proposed advance directives.

6) Limitations

There are limitations to the study's methodology which may affect results and generalizations from the results. Specific limitations are:

²¹²Appendix D presents a list of the quantitative survey question numbers according to subject.

²¹³Respondents were instructed to give spontaneous responses, in their own words, without the use of dictionaries or other reference sources.

- 1) Respondents may try to please the interviewer or to give the "correct" answer. For this reason, respondents' answers may not reflect their true knowledge, attitudes, or opinions.
- 2) Because survey questions touch upon sensitive issues, they are subject to social desirability bias. Respondents may give answers that conform to social norms rather than expressing their true opinions.
- 3) Demographic data occur only in the HCP survey, consisting solely of questions regarding respondents' practice (i.e., physician, nurse, technologist, etc.) and specialty area. Variables such as respondents' age, sex, number of years in practice, educational level, or religious affiliation may influence respondents' choices.
- 4) Sample sizes between the different study groups appear to be disproportionate. However, the pool of individuals available for sampling varies considerably from group to group. There is a considerably larger number of health care professionals than emergency medical services personnel and medical lawyers. When this factor is taken into consideration, the sample sizes are not disproportionate.
- 5) There is no attempt to compare intra-group differences within the health care professional sample. Two international studies, one dealing with

physicians²¹⁴ and the other with nurses,²¹⁵ noted significant differences according to practice area and degree, duration and intensity of patient contact and health care provider-patient interaction. Such analysis is beyond the scope of this study.

- 6) Discrepancies in percentages occur for the following reasons:
 - 1) respondents' failure to answer all survey questions;
 - 2) multiple responses to the same question;
 - 3) rounding error.

7) Results

A) Comparative Quantitative Analysis

1 > Understanding of Medical Treatment Choices

In a legal context, medical treatments are deemed to be neither ordinary nor extraordinary but are viewed in terms of whether the treatment is a benefit or a burden to the patient:

...proportionate treatment is that which, in the view of the patient, has at least a reasonable chance of providing benefits to

²¹⁴Alemayehu, supra note 72.

²¹⁵Lever, J.A., D.W. Molloy, M. Eisenmann et al. Variability in Nurses' Decisions About the Care of Chronically Ill Elderly Patients: an International Study 1992 8 *Humane Medicine* 138.

the patient, which benefits outweigh the burdens attendant to the treatment. Thus, even if a proposed course of treatment might be extremely painful or intrusive, it would still be proportionate treatment if the prognosis was for complete cure or significant improvement in the patient's condition. On the other hand, a treatment course which is only minimally painful or intrusive may nonetheless be considered disproportionate to the potential benefits if the prognosis is virtually hopeless for any significant improvement in condition.²¹⁶

In a medical context, different technologies are governed by different decision-making strategies. A continuum exists with non-invasive treatments at one end of the scale and highly invasive treatments at the other end, with formal written consent being required for the latter and forgone for the former. This is illustrated by comparing two different modes of supplying artificial hydration and nutrition.²¹⁷ Gastrostomy tube placement requires surgical intervention and prior written consent while nasogastric intubation merely involves insertion of a tube into a bodily orifice and does not require written consent.²¹⁸

I anticipated that, when asked whether a specific medical technology constituted extraordinary or ordinary treatment, a small percentage of respondents would state that it depends on the patient's condition and purpose of the treatment; and that the majority

²¹⁶Barber and Nejdil v. Superior Ct. of California (1983) 147 Cal. App. 3d 1006, 195 Cal. Rptr. 484 (1983), at 491.

²¹⁷See Appendix A for definitions of artificial hydration and nutrition, invasive and non-invasive procedures.

²¹⁸Steinhart, A.H., J.P. Baker and A.S. Detsky "Nutritional Therapies" in Ramsey, P.G. and E.B. Larson (Eds.) Medical Therapeutics 1993 Philadelphia: Saunders, at 476.

of respondents would categorize specific medical treatments as either ordinary or extraordinary, depending on the degree of procedural invasiveness involved. This is borne out by the study results.²¹⁹ For example, 66% of HCPs and 68% of EMSP classified mechanical ventilation, a highly invasive treatment, as extraordinary. In contrast, 5% of HCPs and 13% of EMSP classified non-invasive diagnostic procedures as extraordinary.

Between 7-19% (mean 10-12%) of HCPs stated that whether a treatment is ordinary or extraordinary depends on the consequences to the patient (Appendix E, Table 2). Of the EMSP group, a mere 3% stated that two types of treatment, intubation and mechanical ventilation, could be considered either ordinary or extraordinary depending on the purpose for their use. They classified all other treatment modes as either ordinary or extraordinary.

The "it depends" response is the one that is in accordance with the legal position:

what is ordinary and extraordinary must be judged not 'in itself' but in the context of each case and, in particular, on the basis of what is reasonable under the circumstances....The distinction is not a medical one, made on objective criteria, but rather a moral and social one, based on individual, subjective values and beliefs.²²⁰

²¹⁹See Appendix E, Tables 1 and 2.

²²⁰Ferguson, G. Right to Treatment: Re Stephen Dawson 1985-6 Health Law in Canada 55, at 60.

As noted supra, tube feeding comprises a form of artificial hydration and nutrition. Whether or not tube feeding is a medical treatment or comfort care measure²²¹ has been the subject of debate.²²² Due to the symbolic meaning associated with food and water, some people argue that it is not a medical treatment but rather, simply an alternative to traditional meals.²²³ However, the consensus, both medically and legally, is that tube feeding is a medical treatment.²²⁴

From a medical point of view, several health care professional associations have endorsed the position that artificial nutrition and hydration constitutes a medical treatment.²²⁵ Tube feeding is deemed to be a medical treatment for the following reasons. The insertion of a feeding tube requires the skill of a trained health care professional, with placement of some types of tubes necessitating surgical intervention. Misplaced or incorrectly placed tubes can cause complications such as infection, aspiration pneumonia and death. Other complications include congestive heart failure as well as fluid, electrolyte and metabolic imbalances.²²⁶

²²¹See discussion infra under Comparative Qualitative Analysis.

²²²Steinbrook, R. and B. Lo. Artificial Feeding -- Solid Ground, Not a Slippery Slope 1988 318 N.E.J.M. 286, at 288.

²²³Anderson, K.M. Medico-Legal Dilemma: When Can "Inappropriate" Nutrition and Hydration Be Removed in Indiana? 1992 67 Indiana L.J. 479, at 490.

²²⁴Steinbrook and Lo, supra note 222, at 288.

²²⁵Meisel, supra note 157, at 345.

²²⁶Anderson, supra note 223, at 487.

From a legal viewpoint, tube feeding has been judicially recognized as a medical treatment. This was first stated in the California case, Barber and Nejd:

Medical procedures to provide nutrition and hydration are more similar to other medical procedures than to typical human ways of providing nutrition and hydration.²²⁷

Subsequently, in the New Jersey case, In Re Conroy, the New Jersey Supreme Court asserted:

Once one enters the realm of complex, high-technology medical care, it is hard to shed the "emotional symbolism" of food. However, artificial feedings such as nasogastric tubes, gastrostomies and intravenous infusions are significantly different from bottle feeding or spoonfeeding -- they are medical procedures with inherent risks and possible side effects, instituted by skilled health care providers to compensate for impaired physical functioning. Analytically, artificial feeding...can be seen as equivalent to artificial breathing by means of a respirator. Both prolong life through mechanical means when the body is no longer able to perform a vital bodily function on its own.²²⁸

This position was reiterated in a series of American cases involving either a competent patient's request (Bouvia)²²⁹ or, more often, a request made by the surrogate decision-makers of an incompetent patient for removal of a feeding tube (for example --

²²⁷Barber and Nejd, *supra* note 216, at 490.

²²⁸In Re Conroy, *supra* note 21, at 1236.

²²⁹Bouvia v. Superior Court 179 Cal. App. 3d 1127, 255 Cal. Rptr. 297 (Cal. App. 1986).

Brophy,²³⁰ In Re Jobes,²³¹ In Re Guardianship of Browning²³²), culminating in the U.S. Supreme Court decision in Cruzan.²³³

Despite the judicial recognition of tube feeding as a medical treatment, many of the early American living wills statutes specifically excluded artificial hydration and nutrition from the forms of treatment that a person could refuse by means of an advance directive.²³⁴ As noted supra, statutory amendments subsequent to Cruzan have changed this.²³⁵

Opponents to this viewpoint argue that artificial hydration and nutrition constitutes a basic comfort care measure not a medical treatment.²³⁶ In reality, as noted supra, tube feeding is unequivocally a medical treatment, requiring the skill and care of health care professionals to implement it. Nonetheless, it can also serve as a comfort care measure, depending on the patient's condition and the purpose for which it is used. Thus, it is

²³⁰Brophy v. New England Sinai Hospital 398 Mass. 417, 497 N.E.2d 626 (Mass 1986).

²³¹In Re Jobes 108 N.J. 394, 529 A2d 434 (1987).

²³²In Re Guardianship of Browning 543 So. 2d 258 (Fla. D.C.A. 1989); 568 So. 2d 4 (Fla. Sup. Ct. 1990)

²³³Cruzan, supra note 158.

²³⁴Francis, supra note 34, at 33-34.

²³⁵Meisel, supra note 157, at 344-345.

²³⁶Anderson, supra note 223, at 490.

never solely a comfort care measure but rather, it is a medical treatment that can be used to give comfort or supportive care to a patient in certain circumstances.

HCP respondents were asked whether tube feeding is a medical treatment, comfort care measure or both. While 10% stated that it is a comfort care measure only and 38% stated that it is a medical treatment only, the majority (49%) stated that it is both, depending on the clinical circumstances.²³⁷ These results indicate a good understanding and comprehension of this form of medical therapy.

Seven of the majority respondents elaborated their reasoning for this position, giving clinical examples.²³⁸ Four stated that it depends on the nature of the patient's condition -- for example, in the case of an acute, treatable illness, tube feeding is a medical treatment while in the case of a terminal illness, it is a comfort care measure. The remaining three stated that tube feeding can be used as a comfort measure for psychological reasons -- to enhance a patient's sense of self-worth, to allow a patient with a bowel obstruction to enjoy the taste of food, and to provide comfort to family members who may feel better if the patient is getting tube feedings despite patient discomfort.

²³⁷See Appendix E, Table 3.

²³⁸See Appendix F, Table 1.

2 > Legal Status of Advance Directives²³⁹

A majority of respondents stated that advance directives are legally binding. Most stated that written directives are legally binding with a minority stating that oral directives and public statements of treatment choices are legally binding and should be honoured.

Much of the case law regarding treatment choices of non-autonomous patients, including the House of Lords case, Bland,²⁴⁰ and the U.S. Supreme Court case, Cruzan,²⁴¹ involves oral directives. In the New York case, In Re Eichner, the N.Y.C.A. held that public oral declarations made by a non-autonomous patient prior to his incompetency constituted a valid and legally binding expression of his treatment choices.²⁴²

The majority of respondents stated that patients should bear the onus for informing health care providers of the existence of a directive. This is the legal position in Canadian jurisdictions with advance directives legislation.

The majority stated that they were aware of and are in favour of Manitoba's advance directives legislation. The majority of HCPs became aware of the Act through the media, with only 18% learning of it from their professional organizations or their

²³⁹See Appendix E, Table 4.

²⁴⁰Bland, *supra* note 2.

²⁴¹Cruzan, *supra* note 158.

²⁴²In Re Eichner 420 N.E. 2d 64 (1981 N.Y.C.A.), at 68.

employers while most EMSP learned of it from their employers. Only 1% of HCP and 3% of EMSP respondents stated that they had input into the drafting of the Manitoba Act. The majority stated they should have had input.

A majority of respondents indicated that they were aware of and understood the meaning of the term "living will." Most respondents stated that they were familiar with the term "advance health care directive." Less than half stated that they understood the term "durable power of attorney." When asked to define the latter term, all but two respondents defined a power of attorney for financial purposes.

One HCP referred to a patient with an advance directive on his chart and stated that the health care team were "doing everything completely opposite to what the document says." The patient was competent and the HCP did not understand that an advance directive becomes effective only when the patient becomes decisionally incompetent. He stated that his understanding was that an advance directive outlined treatment decisions in anticipation of illness or hospitalization -- that it was a directive made in advance of actual treatment -- but he did not understand that the directive takes effect only upon the patient becoming decisionally incompetent. Discussion with other HCPs revealed that this seems to be a fairly common misconception. The medical literature supports this finding. Dubler described an actual clinical case in which the treatment team followed a competent patient's advance directive over his contemporaneously expressed wishes.²⁴³

²⁴³Dubler, supra note 63, at 23-24.

Both HCP and EMSP respondents indicated that they had a good understanding and comprehension of both civil and criminal liability of health care professionals for failure to follow a patient's advance directive. The majority stated that they believe that health care team members could be found civilly liable for failure to follow directives.

Less than 50% of respondents stated that they believe that following a person's treatment refusal choices when treatment is likely to be completely successful is equivalent to assisted suicide. A minority of respondents stated that they believe that health care team members could be held criminally liable for following such a directive.

Fewer than half of all respondents stated that the medical team has the authority to administer treatment in an emergency situation despite an incompetent patient's prior expressed wishes. In accordance with the Malette case, Canadian HCPs are legally bound to honour such treatment choices in an emergency situation if they are aware of them.²⁴⁴ This finding indicates that HCPs have a good understanding of this position. However, this area is fraught with difficulty for them, as noted infra in the Autonomy discussion.

These results indicate that, while HCPs and EMSP have a good understanding and comprehension of some legal concepts regarding advance directives, they have a somewhat limited understanding of other aspects. One area of limited understanding involves the implementation of advance directives. As noted supra, many respondents do not

²⁴⁴Malette, supra, note 101.

understand what a durable power of attorney for health care is, confusing the term with the traditional power of attorney for financial purposes. Many HCPs also indicated that they do not understand that a patient's advance directive becomes effective only when he or she becomes decisionally incompetent. These misconceptions could give rise to potential problems in the clinical setting when HCPs are called upon to implement such directives.

3 > **Institutional Policy Formulation**²⁴⁵

While the majority of respondents stated that health care institutions should have formal policies mandating that all persons be asked on admission whether or not they have an advance directive (as is the mandate of the American Patient Self-Determination Act²⁴⁶), in reality, this is not the case. A survey of Canadian public general hospitals revealed that while approximately 50% have Do-Not-Resuscitate (DNR) policies, a mere 2.6% have policies with respect to other life-sustaining treatment or advance directives.²⁴⁷ Of the DNR policies, 89% are restricted to patients considered to be "terminally" or "hopelessly" ill and do not reflect the fact that all people have the legal right to forgo life-sustaining treatment.²⁴⁸

²⁴⁵See Appendix E, Table 5.

²⁴⁶Omnibus Budget Reconciliation Act of 1990, *supra* note 159.

²⁴⁷Rasooly, I., J.V. Lavery, S. Urowitz et al. Hospital Policies on Life-Sustaining Treatments and Advance Directives in Canada 1994 150 C.M.A.J. 1265, at 1267.

²⁴⁸Ibid., at 1269.

4 > Bioethical Concepts

A. Autonomy²⁴⁹

Dickens distinguishes value differences between health care professionals and lawyers which stem from differences in the educational orientation and practice modes of these seemingly disparate professions. He states that health care professionals focus on their patients' best interests and are not patient autonomy based, whereas lawyers focus on personal autonomy as the ultimate value and clients' best interests do not enter into the lawyer-client relationship.²⁵⁰

An overwhelming majority of all respondents stated that they think people want to exert greater control over health related decision-making, that this is desirable, and that it is appropriate for patients to have control over aggressive treatment, cardio-pulmonary resuscitation (CPR), and life-prolonging, non-aggressive medical treatment.

It is noteworthy that fewer lawyers than HCPs and EMSP think that people should have control over life-prolonging, non-aggressive treatment. Given the judicial recognition of a patient's right to refuse this type of treatment and the legal profession's

²⁴⁹See Appendix E, Table 6.

²⁵⁰Dickens, B.M. Patients' Interests and Clients' Wishes: Physicians and Lawyers in Discord 1987 15 Law, Medicine and Health Care 110, at 114.

strong autonomy base, one would expect lawyers to favour patient control in this area more strongly.

A minority of all respondents stated that most people are sufficiently well informed regarding medical technology to be able to make truly informed advance directives. Thus, a significant proportion of all three professional groups think that most people lack sufficient knowledge regarding complex medical technology to make such directives.

The majority of respondents stated that there are occasions when it is necessary and appropriate to treat people against their will. While a majority of HCPs and EMSP support this position, the percentages are less than for the lawyer group. In accordance with Dickens' theory, one would expect that HCPs and EMSP would favour this position more strongly than lawyers.

A minority of respondents stated that HCPs should have the discretion to override advance health care directives if they think it necessary for the patient's best interests. These results are in keeping with what one would expect, with the lawyer group showing the least support for this position.

However, a majority of HCP and lawyer respondents and a minority of EMSP stated that HCPs should have the discretion to override a living will if the professional thinks the patient lacked sufficient understanding of the proposed treatment at the time the directive was made.

The majority of all groups stated that it may be appropriate for medical team members to "take over" and make decisions when patients experience a high degree of trauma and stress because these factors render individuals decisionally incompetent.

A minority of all respondents stated that the expertise of HCPs gives them greater authority than patients with regard to medical treatment decisions. The majority stated that HCPs' expertise gives them greater knowledge but not greater authority.

As to who should decide what a patient's best interests are, the majority of HCP and lawyer respondents favour joint decision-making between the patient, the family and the medical team. The EMSP group were almost evenly divided between joint decision-making and patient only decision-making. A minority of HCP and lawyer respondents support patient only decision-making. On the basis of Dickens' theory, one would expect lawyers to favour "patient only" decision-making more strongly.

One of the respondents who supported joint decision-making between the patient and the medical team only, excluding family members from the process, stated: "I think families should stay out of it unless the patient is incompetent." He related clinical experiences where decision-making for competent patients either involved "everyone but the patient" or the patient was the last person to be consulted, creating agonizing conflicts and dilemmas for health care professionals whose first duty is to their patient, not to the family or anyone else.

Several respondents stated that the exclusion of patients from treatment choice decisions is not an unusual occurrence in clinical practice, especially with elderly patients. They stated that some clinicians find it difficult to discuss treatment issues -- especially those related to life-sustaining treatment -- directly with patients and prefer discussion with family members. Zinberg notes that it is not unusual for family members to request treatment that is contrary to a patient's preferences.²⁵¹ When this happens, the health care team may confuse patient needs with family needs.²⁵²

What this means in the context of non-autonomous patients is that a patient's prior expressed treatment choices may be overridden in favour of conflicting choices voiced by family members. One HCP stated:

We always ignore living wills. We ask the family what they want and we always do what the family wants regardless of what the patient wanted. If the patient is comatose or unable to communicate, it doesn't really matter what that person would want. If the patient is in that condition, there's nothing he can do if you ignore his wishes. But if you don't do what the family wants you can be sued. For this reason, the family's wishes always come before the patient's.

The majority of all respondents stated that anyone should be able to execute an advance directive and that this right should not be restricted to terminal patients. A minority stated that a person's age should be taken into consideration when deciding whether or not to adhere to his or her living will.

²⁵¹Zinberg, supra note 36, at 481.

²⁵²Rushton, C.H. Critical Care Nurse as Patient Advocate 1994 14(6) Crit. Care Nurse 102, at 105.

A minority of all respondents stated that they would be reluctant to follow or draft a person's living will if they disagreed with the person's treatment choices, thus indicating a strong orientation towards respecting patient autonomy by all three groups.

These results indicate that all three professional groups have a very strong orientation towards maximizing the goal of patient autonomy and that, contrary to Dickens' position, lawyers are not more strongly autonomy based than HCPs and EMSP. The results indicate that lawyers are concerned not only with fulfilling their clients' wishes but also with doing what is in their client's best wishes. Of the three groups, the EMSP appear to have the greatest orientation towards patient autonomy.

Futility and the Right to Demand Non-Beneficial Treatment²⁵³

A minority of all respondents stated that patient requests for futile treatment should be followed. This is consistent with the medico-legal position that patients do not have the right to demand non-beneficial treatment.²⁵⁴

²⁵³This is a sub-issue of patient autonomy. It is discussed separately due to the depth and complexity of the topic.

²⁵⁴Brett, A.S. and L.B. McCullough. When Patients Request Specific Interventions: Defining the Limits of the Physician's Obligation 1986 315 N.E.J.M. 1347, at 1350.

Health care providers do not usually offer patients the choice of a therapeutic versus a non-therapeutic intervention. Only treatment which is potentially beneficial is offered. Cardio-pulmonary resuscitation (CPR) is an exception. The current policy in most North American health care facilities is that all patients are to be resuscitated in the event of a cardiac arrest unless consent is obtained for a Do-Not-Resuscitate order.²⁵⁵ However, CPR has a 0-10% success rate in the presence of certain underlying medical conditions, such as malignancy, neurologic disease, renal failure, respiratory disease, and sepsis.²⁵⁶ The Canadian Medical Association has proposed a reversal of this policy and practice.²⁵⁷ One HCP respondent strongly advocated endorsement of this proposal and spoke at length regarding the issue of futile treatment.

Respect for patient autonomy does not include the right to demand inappropriate medical treatment.²⁵⁸ Offering non-beneficial or futile treatment gives mixed messages to patients and surrogates and asks them to make medical judgements they are not qualified to make, thus undermining rather than enhancing autonomous choice.²⁵⁹

²⁵⁵Emergency Cardiac Committee and Subcommittees, American Heart Association. Guidelines for Cardiopulmonary Resuscitation and Emergency Cardiac Care 1992 268 J.A.M.A. 2171, at 2284.

²⁵⁶Moss, A.H. Informing the Patient About Cardio-pulmonary Resuscitation: When the Risks Outweigh the Benefits 1989 4 J. Gen. Intern. Med. 349, at 351.

²⁵⁷Canadian Medical Association. Statement on Resuscitative Interventions 1994 151 C.M.A.J. 1176A.

²⁵⁸Senn, J.S. Writing "No-CPR" Orders: Must Resuscitation Always be Offered? 1994 151 C.M.A.J. 1125, at 1126.

²⁵⁹Tomlinson, T. and H. Brody. Futility and the Ethics of Resuscitation 1990 264 J.A.M.A. 1276, at 1276-1278.

Problems occur in defining futility. There is no universal consensus as to what objective criteria constitute futile treatment.²⁶⁰ Youngner defines futility in terms of treatment goals and posits several meanings of futility, ranging from physiologic futility to a remote chance of achieving treatment goals to the "absolute inability to postpone death."²⁶¹ Veatch and Spicer distinguish two types of medically futile care: 1) care that produces no demonstrable physiologic effect; and 2) care that produces a physiologic effect but no net benefit.²⁶²

The determination of what constitutes futility is complex, subjective and value-laden. Patients may choose to risk improbable or transient treatment success in order to obtain a few extra hours or days of life whereas caregivers' goals may be framed in terms of physiological outcomes.²⁶³ It is more than a medical judgment, embracing religious, philosophical, moral and ethical dimensions.²⁶⁴ Thus, the concept of futility includes much more than statistical probabilities and has many layers of meaning for both patients and caregivers, encompassing both quantitative and qualitative aspects.

²⁶⁰Truog, R.D., A.S. Brett and J. Frader. Problem with Futility 1992 326 N.E.J.M. 1360, at 1360.

²⁶¹Youngner, S.J. Who Defines Futility? 1988 260 J.A.M.A. 2094, at 2094.

²⁶²Veatch, R.M. and C.M. Spicer. Medically Futile Care: the Role of the Physician in Setting Limits 1992 18 Am. J. Law & Medicine 15, at 15.

²⁶³Faber-Langendoen, K. Resuscitation of Patients with Metastatic Cancer: Is Transient Benefit Still Futile? 1991 151 Arch. Intern. Med. 235, at 237.

²⁶⁴Schneiderman, L.J., N.S. Jecker and A.R. Jonsen. Medical Futility: Its Meaning and Ethical Implications 1990 112 Ann. Intern. Med. 949, at 951.

B. Decisional Competency²⁶⁵

Like the futility debate, the area of competency is fraught with difficulties. Factors such as stress, pain and emotional states may affect a patient's decision-making capacity. For instance, a patient may be so emotionally impaired by fear that he or she is unable to make informed medical treatment decisions²⁶⁶ and external stressors such as the clinical setting itself may contribute to alterations in decision-making ability.²⁶⁷ It is not uncommon for people to experience shock, disbelief and denial upon the diagnosis of a chronic, disabling, or incurable medical condition.²⁶⁸ Nonetheless, autonomy is not necessarily diminished by the presence of stress, depression, fear or grief. HCPs have a legal duty to respect patients' treatment choices, even though they are anxious, depressed, afraid or grieving, and a concomitant duty to ensure that such choices are truly informed.²⁶⁹

Many respondents expressed concerns about the effect of the aforementioned factors on decisional competency. They stated that they want to be absolutely certain that their patients have full understanding and comprehension of the consequences of their

²⁶⁵See Appendix E, Table 7.

²⁶⁶Brock, D.W. and S.A. Wartman. When Competent Patients Make Irrational Choices 1990 322 N.E.J.M. 1595, at 1597.

²⁶⁷Mendelson, supra note 186, at 127.

²⁶⁸Brock and Wartman, supra note 266, at 1597.

²⁶⁹Kleiman, I. Right to Refuse Treatment: Ethical Considerations for the Competent Patient 1991 144 C.M.A.J. 1219, at 1221-1222.

decisions. Some equated depression with decisional incapacity. But, as Lo states, not every depressed patient has impaired decisional capacity, and an individual's right to informed consent in medical decision-making is not lost simply because the individual is depressed.²⁷⁰

Patients are entitled to have idiosyncratic value systems and beliefs that conflict with accepted medical or popular wisdom. The right to informed medical consent and refusal would be meaningless if we did not respect these rights.²⁷¹ The fact that a treatment choice does not make sense to HCPs is not sufficient to establish decisional incompetency and to justify overriding that choice.²⁷² Health care providers' values are irrelevant. Rationality depends not on what others conceive it to be but on consistency with an individual's own goals, values and premises:

No matter how crazy the starting point and no matter how crazy the final decision, autonomy may still be present if the route from one to the other is rational. The rationality involved relates to the patient's ideas about what is rational and not ours.²⁷³

²⁷⁰Lo, B. Assessing Decision-Making Capacity 1990 18 Law, Medicine & Health Care 193, at 198.

²⁷¹Ibid., at 196.

²⁷²Brock and Wartman, supra note 266, at 1599.

²⁷³McKnight, C.J. Autonomy and the Akratic Patient 1993 19 J. Med. Ethics 206, at 207.

Nonetheless, HCPs do have an obligation to ensure that a patient's seemingly irrational treatment choices are not based on misinformation.²⁷⁴

Some HCPs think that it is acceptable for them to override seemingly irrational decisions made by competent patients on the basis that they may be thankful at some future time. This viewpoint is not supported in the medical literature.²⁷⁵

While the majority of HCP and EMSP respondents stated that, in general, the shock and trauma associated with severe, acute injuries causes decisional incompetency, only 33% of lawyers agreed. The majority of HCPs and a minority of EMSP and lawyers stated that the severe pain and trauma associated with a specific clinical condition, myocardial infarction,²⁷⁶ renders people decisionally incompetent.

A minority of HCP respondents stated that they would be reluctant to follow a patient's advance directive if there was an indication that the patient may have changed his mind between execution of the document and the time of the treatment decision. Lawyer respondents were asked whether HCPs ought to have the discretion not to follow a patient's living will for this reason. Less than half answered yes.

²⁷⁴Kleiman, *supra* note 269, at 1221.

²⁷⁵Chouinard, A. Bioethics in the Critical Care Unit: "Damned if You Do, Damned if You Don't" 1988 139 C.M.A.J. 1180, at 1180.

²⁷⁶See Appendix A.

This issue is illustrated in the New York case of In Re O'Connor.²⁷⁷ Prior to becoming non-autonomous, Mrs. O'Connor voiced her objection to being kept alive by artificial means if unable to care for herself, stating that it is "monstrous to keep someone alive...by using machinery...if they [are] not going to get better"²⁷⁸ and that she "would never want to lose [her] dignity or be a burden."²⁷⁹ The court refused to allow treatment to be discontinued on the basis that Mrs. O'Connor may have changed her mind "so that her past statements do not indicate her present wishes."²⁸⁰

This issue may come to the fore with respect to patients with chronic, disabling illnesses. A person may execute an advance directive for treatment refusal in the event of clinical deterioration that may not occur for many years. However, with progression of the disease state, he or she may come to accept a different level of disability than initially thought, and consequently a directive executed in the initial stages of the illness may not truly reflect his or her current treatment choices.

This underscores the importance of encouraging the revision and updating of advance directives. Singer states that, at the time of execution, people should be advised to revise and update their advance directives to reflect their current treatment choices and

²⁷⁷In Re O'Connor 534 N.Y.S. 2d 886 (Ct. App. 1988) (also known as In Re Westchester County Medical Center)

²⁷⁸Ibid., at 901-902.

²⁷⁹Ibid., at 901.

²⁸⁰Ibid., at 896.

proxy decision-maker preferences in the event that these change over time.²⁸¹ This viewpoint was affirmed by several respondents who stated advance directives should be updated regularly in order to be meaningful and useful to HCPs.

C. Resource Allocation²⁸²

The right of access to medical care is limited by the availability of medical resources. While "health needs and desires are virtually limitless,"²⁸³ medical resources and supplies are not. This gives rise to the allocation of resources by means of rationing and triage.²⁸⁴ Rationing involves limiting the types of resources available. One example involves the use of diagnostic procedures. Physicians will usually order the least costly procedures available and will progress to more costly procedures only if the less costly ones prove to be ineffective. Triage involves prioritizing who gets which treatments by means of a system of objective criteria. For example, in determining which candidates will receive expensive transplant procedures, criteria such as the likelihood of success, the patient's general state of health and lifestyle factors may be considered.²⁸⁵

²⁸¹Singer, supra note 40, at 113.

²⁸²See Appendix E, Table 8.

²⁸³Beauchamp and Childress, supra note 18, at 364.

²⁸⁴Ibid., at 363.

²⁸⁵Ibid., at 380.

The majority of all respondents stated that the right to extraordinary medical treatment should be balanced against the availability of scarce resources.

5 > Hypothetical Treatment Scenarios²⁸⁶

A. Vague v. Specific Wording

The problems with respect to vague v. specific wording in advance directives are discussed supra in Chapter 2, under Advantages and Disadvantages of Advance Directives.

While the majority of HCPs (51%) stated that they would feel comfortable following instructional directives that simply state "no heroic measures," a minority of EMSP and lawyers agreed. Both HCPs and EMSP indicated a much greater comfort level with following treatment specific instructional directives.

B. Withholding v. Withdrawing Treatment

Withdrawal and withholding of medical treatment are ethically the same.²⁸⁷ Nonetheless, HCPs may experience more or less difficulty following patients' directives for either withholding or withdrawing medical treatment for a number of reasons. One factor is medicine's focus on aggressive treatment. Medicine's traditional orientation is

²⁸⁶See Appendix E, Table 9.

²⁸⁷Emergency Cardiac Committee and Subcommittees, American Heart Association, supra note 255, at 2286.

to save life at all costs, viewing disease and death as enemies to be vanquished.²⁸⁸ Only very recently have issues related to dying and comfort care as an alternative to intensive medical care been addressed in the curricula of medical, nursing and other health care educational programs.²⁸⁹ Another factor is uncertainty of diagnosis and prognosis. It is not always possible to predict the outcome of a particular illness for a particular patient, and it is difficult to predict accurately how one will react when actually faced with a particular illness rather than dealing with it in the abstract.²⁹⁰ For these reasons, HCPs have difficulty with the concept that it may be best to do less, rather than more.²⁹¹ Thus, they may experience difficulty in honouring patient requests not to initiate treatment.

While just over half of EMSP and lawyer respondents stated that a living will to withhold treatment should be followed in cases in which complete recovery is likely if the treatment is administered, only 42% of HCP respondents agreed with this position. An overwhelming majority of all respondents stated that living wills for treatment withdrawal should be followed. Thus, it is apparent that respondents in all groups are more comfortable with advance directives directing treatment withdrawal than for withholding of treatment.

²⁸⁸Molloy, W. Vital Choices: Life, Death and the Health Care Crisis 1993 Toronto: Penguin, at 256-257.

²⁸⁹Wanzer, S.H., D.D. Federman, S.J. Adelstein et al. Physician's Responsibility Toward Hopelessly Ill Patients -- a Second Look 1989 320 N.E.J.M. 844, at 844.

²⁹⁰Molloy, supra note 288, at 232-233.

²⁹¹Wanzer, S.H., Adelstein, S.J. and R.E. Cranford. Physician's Responsibility Toward Hopelessly Ill Patients 1984 310 N.E.J.M. 955, at 956.

A majority of lawyers stated that they would feel comfortable drafting the instructional directive of a 20-year-old woman for the refusal of initiation of intubation and mechanical ventilation following acute trauma such as a motor vehicle accident, but less than half of HCPs stated that they would feel comfortable implementing such a directive.

When the scenario is changed such that the young woman would accept intubation and mechanical ventilation but requests treatment withdrawal if there is no clinical improvement after one week, most HCPs stated they would feel comfortable following this directive. This increase in positive responses appears to indicate that HCPs have more difficulty following a directive to withhold treatment altogether than one directing treatment withdrawal.

C. High Technology v. Low Technology

While most lawyers stated that they would feel comfortable drafting the instructional directive of a 20-year-old woman for the refusal of initiation of intravenous therapy and tube feedings following acute trauma such as a motor vehicle accident, only 38% of HCPs agreed. These results are consistent with those for withholding a high technology treatment (mechanical ventilation) noted supra and indicate no greater degree of discomfort with following directives for withholding low technology procedures.

The majority of respondents stated that, in general, they would feel comfortable following or drafting an instructional directive to withhold tube feeding. However, there

is a significant decrease in their comfort levels when asked the same question in the context of a specific patient and clinical scenario.

D. Acute v. Chronic Illness

The majority of all respondents stated that they would feel comfortable following the directive of a young man with Huntington's Disease²⁹² who requests withholding of intravenous therapy and tube feedings.

Thus, it appears that these professional groups are more comfortable with following or drafting instruction directives refusing low technology medical therapies for a patient with a chronic, incurable illness than for a young and otherwise healthy person with an acute, treatable illness.

E. "Irrational" Treatment Choices

While the majority of EMSP stated that they would feel comfortable following a young, healthy patient's directive for the refusal of cardio-pulmonary resuscitation in the event of a myocardial infarction,²⁹³ a minority of HCP and lawyer respondents would feel comfortable with this.

²⁹²See Appendix A.

²⁹³Ibid.

A minority of all respondents stated that they would feel comfortable following such a directive if it were oral rather than written. However, the majority of HCP respondents would feel comfortable with it if they knew the patient had a terminal illness.

Thus, most respondents stated that they are more comfortable dealing with written rather than oral directives, although some stated that they might be comfortable with an oral directive but not one expressed in an informal, casual setting.

A majority of HCP and minority of EMSP and lawyer respondents stated that they would feel comfortable following a young alcoholic man's written directive for blood transfusion refusal even though he may hemorrhage to death without transfusion therapy. The majority of HCP and EMSP respondents stated that they believe such a directive is legally binding.

F. Psychiatric Treatment Issues

A minority of respondents stated that they would feel comfortable either honouring or drafting the directive of a psychiatric patient for psychotropic drug refusal. A minority of respondents stated that they believe such directives are legally binding. As noted supra, the Ontario Court of Appeal recognized such directives as legally binding in Fleming.²⁹⁴

²⁹⁴Fleming, supra note 102.

The majority of HCP respondents expressed concerns about patient safety issues, stating that there is a need to balance individual patient needs with those of others (patients and staff) in the immediate environment. Others stated that their disagreement with following such directives was focused on the individual patient's needs, asserting that it is counter-therapeutic not to medicate an agitated, potentially dangerous psychotic patient and that "these drugs may be needed to give the patient a quality of life."

G. Euthanasia

A minority of all respondents stated that they would be comfortable implementing or drafting a patient's directive directing health care providers to do everything possible to relieve pain and suffering even if it meant administering a lethal dose of medication. The majority of EMSP respondents (61%) stated that they believe such a directive is legally binding.

In summary, the responses to hypothetical treatment scenarios correlate with those in the general knowledge base category. These results indicate that HCPs and EMSP are autonomy based. These groups exhibit great willingness to comply with patients' choices but not until thorough, meticulous, and strenuous efforts have been made to ensure that choices are truly reflective of their wishes. Surprisingly, lawyers showed a greater degree of reluctance to comply with clients' idiosyncratic choices than anticipated. Like HCPs, lawyers want to maximize client autonomy but it appears that they also want to ensure that clients are making truly informed, knowledgeable choices.

6> Clinical and Personal Experience with Advance Directives²⁹⁵

A minority of all respondents stated that they either have clinical experience with advance directives or, in the case of lawyers, have represented clients with advance directives. The majority of HCPs and EMSP stated that they were comfortable honouring the directives.

While a minority of all respondents stated that they had their own advance directive, many HCPs and EMSP stated that they have considered executing their own directive. The contents of respondents' actual and proposed advance directives are discussed infra under Comparative Qualitative Analysis.

B) Comparative Qualitative Analysis

1> Respondents' Definitions of Relevant Terminology

Understanding of terminology relevant to advance directives is crucial if such directives are to be honoured. Patients may be subjected to unwanted medical treatment if HCPs do not clearly understand the meaning of certain terms, such as heroic measures, extraordinary measures, aggressive medical treatment, comfort care, best interests of the patient, competent, and persistent vegetative state (PVS). For this reason, a subset of

²⁹⁵The results are summarized in Appendix E, Table 10.

HCP respondents was surveyed to determine their understanding of the meaning of these terms.²⁹⁶

A. Heroic Measures, Extraordinary Measures and Aggressive Medical Treatment

Four respondents described "heroic measures" as cardio-pulmonary resuscitation (CPR). One defined it as to the "usual Code 99²⁹⁷ situation." Twelve respondents stated that "heroic measures" consisted of life-prolonging measures used in situations where the patient has a poor prognosis and/or quality of life is compromised. Six respondents used similar definitions to describe "extraordinary measures" and 13 respondents defined "aggressive medical treatment" this way.

Five respondents described all three terms as medical treatment to sustain or prolong life. Four respondents stated that extraordinary and heroic measures were equivalent, with two defining this to mean life-saving medical interventions and two defining this to mean maximum medical interventions provided to patients with a poor prognosis.

Five respondents defined "extraordinary measures" as medical interventions not customarily used in patient care or outside standard patient management protocols. One respondent gave the example of experimental surgery.

²⁹⁶The results are presented in Appendix F, Table 2.

²⁹⁷See Appendix A.

One respondent stated that he/she had never heard of the term "extraordinary measures." Another referred to "heroic measures" as non-medical interventions and underscored the word "non-medical."

B. Comfort Care

The term "comfort care measures" appears in patient records, including doctors' orders and progress notes; yet it is not found in medical dictionaries. Quill describes comfort care as a "humane alternative"²⁹⁸ to aggressive medical treatment, the goal of which is to promote comfort and lessen suffering rather than to cure disease and prolong life.²⁹⁹ He defines comfort care in terms of its focus and purpose rather than in terms of specific measures:

Comfort care focuses its energy more on the patient's quality of life, personal meaning, and symptom alleviation than on prolonging life or treating disease.³⁰⁰

Medical therapies involved in comfort care are "highly idiosyncratic -- depending on the disease, the individual, the family, and the social environment."³⁰¹ Pivotal to this concept is a philosophy of maximizing patient control, dignity and interaction. Quill voices only one criticism of comfort care measures:

²⁹⁸Quill, T.E. Death and Dignity: Making Choices and Taking Charge 1993 New York: Norton, at 76.

²⁹⁹Ibid.

³⁰⁰Ibid.

³⁰¹Ibid., at 51.

Comfort care is offered to too few patients, often very late in their illness, and only after all conceivable more aggressive medical interventions have been repeatedly tried and failed. It is usually presented as the last resort, with an apology that there is nothing more to do, rather than as a positive, humane alternative approach to the last phase of one's life.³⁰²

Murphy and Price state that comfort care is often presented in a negative manner, with an emphasis on what will not be done -- "do not resuscitate, withhold treatment, no heroics, and there's nothing more we can do."³⁰³ They state that this negativity "reduces the patient to her disease."³⁰⁴ They recommend framing comfort care in positive terms, telling patients that everything possible will be done to maximize their quality of life, and emphasizing what measures will be taken to achieve this goal.³⁰⁵

Respondents' definitions correlate strongly with Quill's, emphasizing patient dignity, control and interaction with others. They stated that comfort care does not consist of specific treatment modalities but rather is tailored to individual patient needs and involves total care, including physical, emotional and spiritual dimensions, and that it is not restricted to institutional settings but may be provided in patients' home. While one respondent stated that comfort care was "not aggressive treatment," another stated that it

³⁰²Ibid., at 99.

³⁰³Murphy, P.A. and D.M. Price 'ACT': Taking a Positive Approach to End-of-Life Care 1995 95(3) A.J.N. 42, at 42.

³⁰⁴Ibid.

³⁰⁵Ibid.

consists of "anything that provides comfort for the patient, which can include aggressive medical treatment."

In keeping with Murphy and Price's position, most respondents framed their definitions in positive terms, stating what can be done rather than framing comfort care in terms of what treatments will not be provided. One respondent stated that comfort care consists of "life support measures/monitors." This is the antithesis of comfort care. Aside from this response, HCPs demonstrated a good grasp of this concept which they describe meaningfully and effectively.

C. Best Interests of the Patient

There are two legal standards for surrogate decision-making for non-autonomous patients. The "substituted judgement" standard requires surrogates to make the best approximation of what the patient would have wanted. This standard is usually applied in cases where the patient had given some indication of his or her treatment preferences prior to incompetency. Evidence taken into consideration includes statements made to family and friends regarding treatment choices as well as the patient's value system, world view and beliefs.³⁰⁶

³⁰⁶Marcus, B. Cruzan: No Right-to-Die for Those Without a Will to Live 1991 38 Wayne L. Rev. 249, at 257-258.

The "best interests" standard is used in cases where there is inadequate evidence to meet the "substituted judgement" standard. The surrogate tries to determine what treatment would be in the patient's best interests. Factors to be considered in making this determination include the relief of pain and suffering, the preservation and potential restoration of function, and the quality of life to be gained or maintained.³⁰⁷

A rich variety of meanings emerged for this term. One respondent accurately stated that the meaning of "best interests" is highly individualized, varying from one patient to another and from one clinical situation to another. Most respondents gave patient autonomy based definitions. Four respondents provided non autonomy based definitions which put health care provider interests ahead of patient interests.

Seven respondents included the phrase "quality of life" in their definitions. One respondent stated that sometimes "best interests" means not preserving life at all costs but providing as dignified a death as is possible. Two respondents referred to the minimizing of suffering.

Eight respondents defined the "substituted judgment" rather than "best interests" criteria. These results seem to indicate that HCPs may have some difficulty in distinguishing between the "substituted judgement" and "best interests" decision-making standards.

³⁰⁷Ibid., at 259.

D. Competent

This seemingly straightforward term poses difficulties because medicine and law use different tests to measure competence. Medically speaking, the test of competence is global and "requires that a person is orientated in space and time, has some degree of rational thought and a reasonable understanding of issues involved."³⁰⁸ Legally speaking, the test of competence is time and task specific and "requires that a person understands (perceives the meaning of) the nature and effect of what he or she is doing or signing."³⁰⁹

Five respondents gave accurate definitions of decisional competency. One respondent correctly stated that a person can make a seemingly irrational or idiosyncratic decisions and still be competent.

One respondent labelled all people with substance abuse problems and all psychiatric patients as decisionally incompetent. Yet one is not rendered incompetent solely by virtue of suffering from a psychiatric illness or a proclivity to substance abuse; it is inappropriate to categorize such persons as decisionally incompetent in such a global fashion.

³⁰⁸Lanham and Woodford, supra note 203, at 664.

³⁰⁹Ibid.

Thus, while some respondents indicated that they have a clear understanding of the concept of decisional competency, many do not. This underscores the more desirable autonomous/non-autonomous terminology which conveys the concept of medical treatment decision-making ability or inability in a clearer, more definitive manner.

E. Persistent Vegetative State³¹⁰

The persistent vegetative state (PVS) is characterized by the presence of brain wave activity and brain stem function controlling the homeostatic mechanisms of circulation, respiration and digestion. PVS patients breathe spontaneously without mechanical ventilatory assistance. While able to digest food, they must be tube fed due to inability to swallow. On the other hand, brain death is characterized by the absence of brain wave activity and brain stem function with consequent inability to control homeostatic functions. Without assisted mechanical ventilation, respiration and circulation quickly cease.³¹¹

Not only have many landmark legal cases on medical decision-making involved PVS patients, but this term occurs with frequency in advance directives, including those of survey respondents.

³¹⁰See Appendix A.

³¹¹Multi-Society Task Force on PVS, supra note 6, at 1502.

Six respondents provided definitions indicating some understanding of the meaning of this term. Many respondents equated PVS with brain death. One described it as a state in which the patient is "unable to sustain his/her own life (respiratory and cardiac function) without mechanical intervention." Several definitions are too brief to ascertain whether the respondents have a clear understanding of the term. While the parameters described are part of what constitutes the PVS state, they are not definitive. None defined it as the result of irreversible cerebral cortical damage with an intact brain stem.

In sum, no respondents provided an accurate definition of PVS. The most common misconception appears to be equating this state with brain death. This is not uncommon as HCPs have difficulty distinguishing the two states.³¹²

This wide-ranging variety of definitions indicates that while, for the most part, HCPs have a good understanding of terminology relevant to advance directives, there are areas of concern. For instance, definitions for the terms "heroic measures," "extraordinary measures," and "aggressive medical treatment" differ somewhat. Most HCPs have a limited understanding of what constitutes a persistent vegetative state (PVS) and of the differentiation between the "substituted judgement" and "best interests" decision-making standards. This underscores the importance of making advance directives that either spell out specific treatment choices in detail or else clarify ambiguous terms. Many respondents did exactly that in their own advance directives -- for example, by

³¹²Chabelewski, F. and M.K.G. Norris. Gift of Life: Talking to Families about Organ Transplantation 1994 94(6) A.J.N. 28, at 29.

stating, "no extraordinary measures" followed with, "by extraordinary measures, I mean....".

2 > Respondents' Actual and Proposed Advance Directives

A. Actual Directives

Of the respondents who have their own advance health care directives, only one directive is written, stating "no extraordinary measures." The remainder are oral expressions of treatment choices to loved ones. While some respondents stated specific treatment choices in their oral directives, many suffer from terminological vagueness -- for example, phrases such as "no futile treatment" and "no heroic measures." Others suffer from lack of specificity with respect to clinical conditions -- for example, "brain damage -> no treatment." One HCP's directive states: "no heroic measures - i.e., cardio-pulmonary resuscitation, chemotherapy;" however, it does not delineate the conditions under which he or she would decline these interventions. The pitfalls associated with vague, non-specific directives are discussed supra under Advantages and Disadvantages of Advance Directives.

The New York case of Evans v. Bellevue Hospital³¹³ further illustrates problems in interpreting and implementing directives using vague, ambiguous terminology. The

³¹³Evans, supra note 88.

hospital defendant administered life-sustaining treatment to a patient despite awareness of his advance directive stating:

...life-sustaining procedures should be withheld or withdrawn if I have illness, disease or injury or experience extreme mental deterioration, such that there is no reasonable expectation of recovering or regaining a meaningful quality of life.³¹⁴

The hospital refused to follow the directive because of ambiguity and difficulty interpreting the phrase, "meaningful quality of life." This may mean one thing to one person and something entirely different to another. If he had specified what "meaningful quality of life" meant to him, leaving no question as to what level of disability he could or could not live with, this patient's advance directive would likely have been honoured.

B. Proposed Directives

The majority of respondents' proposed directives use condition and treatment specific terminology. These directives are precise, detailed and often reflective of respondents' clinical experiences. Many reflect respondents' values orientation, such as statements about independence and quality of life and what this means for the particular respondent. These are ideal instructional directives because they paint a portrait of the individual and his or her values and preferences.

³¹⁴Ibid.

Two HCPs stated that they would use Dr. William Molloy's advance directive form (Appendix B, Example 1). Four respondents (2 lawyers and 2 EMSPs), indicated that they would execute proxy directives. None specified treatment preferences. . . .

There are two unusual directives, one specifying a demand for treatment, and the other an idiosyncratic directive specifying a treatment refusal based on fear of intubation and mechanical ventilation. Four HCP respondents had euthanasia requests in their proposed advance directives.

The results of this study indicate that most HCPs strongly approve of and support patient autonomy and this is reflected in their own actual or proposed advance directives. Some respondents related the profound impact of clinical experiences, where the prior expressed wishes of a non-autonomous patient were not clearly expressed and thus subject to interpretation, resulting in the patient receiving inappropriate treatment. Thus, it is not surprising that health care professionals imbue their own existing or proposed directives with depth, clarity and precision.

8) Conclusions

Advance health care directives are a legal mechanism allowing patients to be in control of medical treatment decision-making in the event of future decisional incompetency. Three hundred health care professionals were surveyed to determine their knowledge and understanding of advance health care directives. The study cohort was

comprised of a variety of health care team members including physicians, nurses, technologists, and pharmacists. The study consisted of both qualitative and quantitative components. The quantitative component consisted of 57 questions requiring a simple yes-no response. These questions were categorized to determine respondents' awareness and knowledge level of advance directives, actual experience with implementation of such directives, and comfort levels in implementing such directives in a variety of hypothetical clinical scenarios involving adult patients in medical, surgical and psychiatric clinical settings. The qualitative component consisted of respondents' definitions of relevant terminology and examples of their actual or proposed advance directives.

The study results suggest that an overwhelming number of health care providers support patient autonomy and decision-making by way of advance health care directives. They demonstrate a good understanding of some aspects of the legal status of advance directives but limited understanding of others. They may have difficulty with the actual implementation of advance directives, especially those involving so-called "irrational" treatment choices and those involving the refusal of medical treatment with a high probability of success as well as those requesting withholding of medical treatment. Due to lack of consensus with respect to terminology relevant to the area of advance directives and lack of understanding of the concept of proportionality and the benefits-burdens test, health care providers may experience difficulty interpreting patients' directives.

As noted supra, Dickens states that health professionals and lawyers represent diametrically opposite viewpoints and approaches with respect to their clientele. His

views are not borne out by this study. Health care professionals and emergency medical services personnel were found to value patient autonomy and lawyers express were found to express concerns regarding clients' best interests to a greater extent than anticipated. All professional groups expressed a high degree of concern and meticulousness in ensuring that patients' or clients' treatment choices reflect their true wishes.

Chapter 6 - Advance Directives: Future Directions

The area of advance health care directives constitutes an exciting, evolving development in the law. Many common law jurisdictions have enacted advance directives legislation and it is likely that others will soon follow suit. However, as the American experience demonstrates, simply enacting statutory law is not sufficient. Fluidity and flexibility are crucial so that legislation can be amended to reflect changing requirements and keep pace with constantly changing developments in the medical sphere.

Manitoba's Health Care Directives and Consequential Amendments Act came into force in 1993. While it is still too early to assess its impact, the Act is significant to both patients and health care providers as regards medical treatment decision-making autonomy and self-determination.

The Manitoba statute was drafted thoughtfully, carefully and with a view to avoiding the pitfalls noted in other jurisdictions. The legislation confers maximum empowerment to those who choose to exercise medical decision-making autonomy through

execution of advance directives with no restrictive clauses such as terminal illness or current condition requirements, and no restrictions regarding medical treatment.

In the U.S., another level of advance directives legislation is emerging as a response to changing needs. Keyserlingk describes such legislation, consisting of statutory amendments as well as new statutes, as second-generation advance directives.³¹⁵ A time may come when Manitoba's statute will undergo a similar metamorphosis, perhaps in the realm of emergency medical treatment. Manitoba's statute has no provisions for pre-hospital advance directives. Emergency medical services personnel often find themselves in difficult situations in which they are legally bound to provide aggressive medical treatment even though inappropriate and unwanted. Enactment of pre-hospital advance directives legislation, by way of amendments to the existing statute or creation of separate legislation, could circumvent this dilemma and, in the process, enhance patient autonomy and alleviate EMSP stress. An example of a pre-hospital advance directive is presented in Appendix G.

Manitoba's Act provides the opportunity to make advance directives in a manner that is as straightforward and uncomplicated as possible. However, a telling criticism of advance directives legislation is that the average person lacks adequate medical knowledge to make informed medical treatment choices such that a directive may not accurately reflect the patient's wishes. The problem is exacerbated by the increasing complexity of

³¹⁵Keyserlingk, E.W., supra note 141, at 57.

medical technologies. One way to circumvent it is to require health care professional input or counselling in advance directive execution.

Statutory amendments requiring or advising health care professional input or counselling in advance directive execution could go a long way to alleviate these concerns. Consultation with health care providers could decrease the use of vague wording and terminology, thereby ensuring clear, precise, non-ambiguous documents. Ease of interpretation enhances the likelihood that a patient's advance directive will be honoured. Ultimately, decision-making belongs to patients, but guidance from health care professionals could benefit and empower patients.

Mandatory updating requirements restrict patient autonomy. For instance, a person could be subjected to undesired medical treatment simply because he forgot to update his advance directive in accordance with statutory requirements. However, absence of updating requirements may result in advance directives that are outdated and not reflective of current treatment choices. Statutorily imposed updating requirements are too restrictive but the statute could be amended to incorporate recommendations to update at regular intervals or on the occurrence of changes in a person's medical condition. This is another area in which health care professional input and counselling could prove advantageous.

As more Canadian jurisdictions consider and enact advance health care directives legislation, Canada may need to implement legislation similar to America's PSDA,³¹⁶ mandating inquiry by health care institutions during the admission process. This statute also has a very clear educational mandate, directing health care facilities to provide education to both staff and patients.

A computerized Canadian data base similar to the American electronic living wills data base could enhance accessibility to patients' advance directives, ensuring that their wishes are known and respected by medical professionals. For a minimal fee, the U.S. National Electronic Archive of Advance Directives provides 24-hour/day, 7-day/week access to advance directives from any touch tone telephone anywhere in the world, the faxing of advance directive documents on demand to any health care facility or person, and a wallet card to inform health care providers and family members how to access advance directives documents.³¹⁷ A similar Canadian data base could be accessible to medical and allied health care professionals, emergency medical services personnel and law enforcement agencies.

³¹⁶Omnibus Budget Reconciliation Act of 1990, supra note 159.

³¹⁷National Electronic Archive of Advance Directives PrepCard: Attorney Registration Kit: Legal Choices to Assure that Your Clients' Wishes Will be Followed 1994

Western society has undergone an unparalleled technological and scientific renaissance in the last 40 years. However, medical reality is such that there are situations where "the ability to prolong life may be a curse instead of a blessing."³¹⁸ One respondent stated that "we go too far with medical technology and do things without considering the consequences of the use of the technology." Another asserted:

Technology cannot advance at an uncontrolled and unthought out means. At times we need to control the use, or limit the use of the technology we have, taking it out of the closet only when most appropriate.

Emerging developments in advance health care directives law provide a way for both patients and health care providers to avoid becoming "prisoners of technology"³¹⁹ and to realize the "delicately balanced fusion of body, mind and soul in human life."³²⁰ These developments are certain to exert a powerful impact on health care professionals and their roles and relationships with patients. Health care professionals will be faced with many complex issues and challenges as advance directives attain increased legal recognition. This study indicates that health care providers welcome such change and strongly support patient autonomy and self-determination and their expression by means of advance health care directives.

³¹⁸Thomson, G.P. Appeal to Doctors 1969 II Lancet 1353, at 1353.

³¹⁹Angell, M. Prisoners of Technology: the Case of Nancy Cruzan 1990 322 N.E.J.M. 1226, at 1228.

³²⁰Jakobovits, I. Jewish Medical Ethics -- a Brief Overview 1983 9 J. Med. Ethics 109, at 112.

Grant me strength, time and opportunity always to correct what I have acquired, always to extend its domain; for knowledge is immense and the spirit of man can extend infinitely to enrich itself daily with new requirements. Today he can discover his errors of yesterday and tomorrow he may obtain a new light on what he thinks himself sure of today.³²¹

Maimonides wrote this eloquent passage in the twelfth century, yet the message imparted is timeless and just as applicable in the twentieth century. As medical technology advances at an ever quickening pace, we are sure to discover our errors of yesterday and shed new light on what we think sure of today. This is especially true with advance health care directives. It is virtually impossible for the maker of a directive to anticipate all possible twists and turns of fate and thus all possible clinical scenarios and treatment decisions. There is an infinite number of possibilities and with it, infinite challenges.

³²¹Maimonides, M. "Prayer of Maimonides" (circa 12th. century) In Reich, w.T. (Editor in Chief) Encyclopedia of Bioethics 1978 New York: Free Press, at 1737-1738.

APPENDICES

APPENDIX A
GLOSSARY OF RELEVANT
MEDICAL TERMINOLOGY

Acquired Immunodeficiency Syndrome (AIDS): AIDS is a universally fatal disease caused by a virus (HIV or human immunodeficiency virus) and transmitted through intimate contact and the exchange of bodily fluids.¹

Advanced Cardiac Life Support (ACLS): This consists of procedures used to maintain breathing and circulation in a person who has had a cardiac or respiratory arrest. It involves procedures of a highly invasive nature, such as the insertion of breathing tubes for mechanical ventilation (endotracheal intubation), the insertion of tubes into the veins, arteries and heart chambers, and the application of electric current to the heart.²

Alzheimer's Disease: This is a progressive neurological disorder characterized by cerebral cortical atrophy causing irreversible dementia, intellectual deterioration and personality disintegration.³

Amyotrophic Lateral Sclerosis (ALS): Also known as ALS or Lou Gehrig's or motor neuron(e) disease, this is a rapid, steadily progressive, neurodegenerative disorder resulting in death within three years for over 80% of patients. It destroys spinal cord and brain stem cells, ultimately resulting in total paralysis, but with no alteration in cognitive awareness.⁴

Artificial Hydration and Nutrition: This is the provision of food and/or fluids enterally (by way of the gastrointestinal tract) and/or parenterally (by way of the circulatory system through a vein). Methods of artificial feeding include nasogastric tubes in-

¹Hollander, H. and M.H. Katz. "HIV Infection" in Tierney, L.M. Jr., S.J. McPhee and M.A. Papadakis (Eds.) Current Medical Diagnosis and Treatment 1995 Norwalk, Conn.: Appleton, at 1106-1107.

²Emergency Cardiac Committee and Subcommittees, American Heart Association. Guidelines for Cardiopulmonary Resuscitation and Emergency Cardiac Care 1992 268 J.A.M.A. 2171, at 2177, 2199.

³Miller-Keane Encyclopedia and Dictionary of Medicine, Nursing and Allied Health 1992 Philadelphia: Saunders, at 57

⁴Cranford, R.E. Neurologic Syndromes and Prolonged Survival: When Can Artificial Nutrition and Hydration Be Forgone? 1991 19 Law, Medicine & Health Care 13, at 20.

serted into the stomach via the nose and surgically implanted stomach (gastrostomy or G-tube) or intestinal (jejunostomy or J-tube) tubes.⁵

Blood Transfusions: This is the introduction of whole blood or blood products directly into the bloodstream to maintain or replace blood volume, to provide blood components, or to improve cellular oxygen transport.⁶

Brain Death: Brain death is defined as loss of all brain function, i.e., of both the cerebral cortex (which regulates higher functions such as perception, cognition and communication) and the brain stem (which regulates physiological functions, such as breathing, circulation and digestion). It is possible to maintain the physiological functions of respiration and circulation by means of mechanical ventilation in a person who is brain dead.⁷

Cardiopulmonary Resuscitation (CPR): CPR is an emergency first-aid technique used to re-establish breathing and circulation in an individual who has experienced cessation of these functions as the result of sudden cardiovascular collapse, electric shock, drowning and other causes. The technique involves blowing air into the affected individual's lungs and maintaining circulation by means of compressions applied to the individual's sternum or breastbone.

This technique is performed until the initiation of ACLS (see *supra*).⁸

Chemotherapy: This term refers generally to the use of chemicals to treat cancer or other diseases.⁹ However, it most often refers specifically to the use of cytotoxic drugs in cancer treatment.¹⁰

⁵Snyder, L. Artificial Feeding and the Right to Die: the Legal Issues 1988 9 J. Legal Med. 340, at 351-352.

⁶Miller-Keane, supra note 3, at 1518.

⁷Cranford, supra note 4, at 14.

⁸Emergency Cardiac Committee and Subcommittees, American Heart Association, supra note 2, at 2177.

⁹Miller-Keane, supra note 3, at 286.

¹⁰Fleming, I.D., L.W. Brady, G.B. Mieszkalski et al. "Basis for Major Current Therapies for Cancer" in Murphy, G.P., W. Lawrence Jr. and R.E. Lenhard Jr. (Eds.) Textbook of Clinical Oncology 1995 Atlanta: American Cancer Society, at 110.

Code: When a hospitalized patient experiences a cardiac arrest, a code procedure is set in motion. A code begins when a health care provider finds a patient in cardiopulmonary arrest, calls for help and begins cardio-pulmonary resuscitation (CPR) (see supra). The phrase "Code 99" or "Code Blue" is paged over the hospital's public address system to summon a code team, consisting of physicians and intensive care nurses, who administer advanced cardiac life support (ACLS) measures (see supra).¹¹

No Code: The terms "No Code," "No 99" or "DNR" (Do Not Resuscitate) refer to physician orders not to perform resuscitation on patients experiencing cardiac or respiratory arrests. These orders are usually written for patients who are unlikely to benefit from resuscitation.¹²

Dialysis: This is a method used in patients with defective kidney or renal function to remove waste products from the bloodstream that are normally removed by the kidneys and secreted in the urine.¹³

Guillain-Barre Syndrome: This is a neurological disorder of unknown cause involving progressive paralysis which starts in the lower extremities and advances upwards, persisting for days, weeks, months or years. Mechanical ventilation is necessary with respiratory muscle involvement. Individual outcome is unpredictable and there is no known curative treatment.¹⁴

Hypodermoclysis: This is a technique of infusing fluids or analgesic medication into subcutaneous tissue,¹⁵ often used in terminal cancer patients to provide continuous morphine infusion when oral or intravenous routes are not appropriate or usable.¹⁶

¹¹Ellstrom, K. and L.D. Bella. Understanding Your Role During a Code 1990 20(5) Nursing 36, at 38.

¹²Anthony, M.L. No Code: Helping the Family Understand What it Means 1993 23 (2) Nursing 42, at 42.

¹³Miller-Keane, supra note 3, at 418-419.

¹⁴Aminoff, M.J. "Nervous System" in Tierney et al., supra note 1, at 872.

¹⁵Fainsinger, R.F. and E. Bruera. Management of Dehydration in Terminally Ill Patients 1994 10 J. Palliative Care 55, at 57-58.

¹⁶Fulton, J.S. and G.B. Johnson. Using High-Dose Morphine to Relieve Cancer Pain 1993 23(2) Nursing 35, at 39.

Huntington's Disease: This is a hereditary neurological disease characterized by degenerative brain cell changes, causing mental deterioration, speech disturbances and chorea (rapid, jerky, involuntary muscular movements). It is latent until the third or fourth decade and causes progressive deterioration over a 15-20 year span, ultimately resulting in total incapacitation and death.¹⁷

Intravenous Therapy: This involves the administration of fluids into a vein by means of a steel needle or plastic cannula. It is used to maintain fluid and electrolyte balance, to correct fluid volume deficits, to provide a route for medication administration or nutritional therapy.¹⁸

Intubation: This is the insertion of a tube into a bodily orifice for various purposes. Endotracheal intubation involves insertion of a tube through the mouth and into the trachea to provide an airway. Gastro-intestinal intubation involves insertion of a tube into the stomach, duodenum or jejunum either to remove excess fluids, gas or blood or for the purpose of feeding in patients who are unable to swallow.¹⁹

Invasive Procedures: These are medical or surgical procedures which involve entry into body tissues, cavities, or organs by means of skin puncture, incisions or insertion of instruments.²⁰

Locked-In Syndrome: This condition arises as a result of a focal brain stem lesion. Affected individuals experience total paralysis and appear to be unconscious but, in reality, they are fully conscious and totally aware of their surroundings but unable to communicate.²¹

¹⁷Miller-Keane, supra note 3, at 706-707.

¹⁸Ibid., at 790.

¹⁹Ibid., at 792.

²⁰Ibid.

²¹Multi-Society Task Force on PVS. Medical Aspects of the Persistent Vegetative State (Part I) 1994 330 N.E.J.M. 1499, at 1501.

Mechanical Ventilation: Mechanical ventilation is used for patients who are unable to maintain adequate ventilation or oxygenation.²² It consists of maintaining a person's breathing by artificial means with the use of a mechanical apparatus referred to as a ventilator or a respirator. The mechanical device is connected to the person via a tube inserted into the person's airway. Air is forced directly into the lungs from the machine through the tubing.²³

Morphine Intravenous Infusion Pump: An intravenous infusion pump is an electronic device that delivers a constant, accurate and pre-selected fluid rate and volume by means of a pressure gradient. Such devices are used for the infusion of fluids, medications, and artificial hydration and nutrition (see supra).²⁴ Morphine infusion pumps are used to provide constant, controlled analgesia to terminal cancer patients.²⁵

Myocardial Infarction (MI): This condition is commonly referred to as a "heart attack" and arises when there is a blockage or thrombus obstructing the coronary arteries supplying the heart muscle with blood. As a result, oxygen does not reach the areas of blockage, causing necrosis or death of heart muscle cells. The necrotic area is referred to as an area of infarction. Myocardial infarction can result in sudden death and must be treated quickly. The preferred form of treatment consists of the administration of thrombolytic drugs (see infra).²⁶

Non-Invasive Diagnostic Procedures: These are procedures which do not utilize invasive techniques (see supra).²⁷

²²Bolton, P.J. and K.A. Kline. Understanding Modes of Mechanical Ventilation 1994 94(6) A.J.N. 36, at 36.

²³Dupuis, Y.G. Ventilators: Theory and Clinical Application 1991 St. Louis: Mosby, at 3-26.

²⁴Suddarth, D.S. (Ed.) Lippincott Manual of Nursing Practice 1991 Philadelphia: Lippincott, at 85.

²⁵Hill Jr., C.S. "Effective Treatment of Pain in Cancer Patients" in Murphy et al., supra note 10, at 677.

²⁶Miller-Keane, supra note 3, at 975-976.

²⁷Ibid., at 1033.

Persistent Vegetative State (PVS): Brain cells must have a constant supply of oxygen. Even a short period (four minutes) of anoxia or oxygen deprivation will cause irreparable damage to the cortex. The brain stem is more resistant to oxygen deprivation and may, therefore, continue to function after irreversible cortical destruction. A person who has sustained irreversible cortical damage but has an intact, functioning brain stem is said to be in a "persistent vegetative state" or PVS. The affected individual has no cognitive function, is unable to feel emotion or pain, is incapable of voluntary movement, speech or communication. He experiences sleep-wake cycles but shows no meaningful responses. Responses to external stimuli are purely reflex. He is able to breathe without the assistance of mechanical ventilation. He is unable to chew or swallow food but is capable of digesting food provided artificially.²⁸

Radiotherapy: This is the use of radiation and radioactive substances in the treatment of cancer and other diseases.²⁹

Thrombolytic Drugs: These drugs act by dissolving blood clots. Two such agents are streptokinase and tissue plasminogen activator (TPA) (see *infra*). Administered intravenously in the early stages of an acute myocardial infarction (see *supra*), they induce vascular re-perfusion, reducing mortality and morbidity associated with this condition.¹²³⁰

Tissue Plasminogen Activator (TPA): TPA is a thrombolytic enzyme produced by recombinant DNA technology and it is the treatment of choice for the treatment of myocardial infarction (see *supra*).³¹

Total Parenteral Nutrition (TPN): TPN is a method of providing total nutritional requirements by the intravenous route through a catheter inserted surgically into one of the

²⁸Multi-Society Task Force on PVS, *supra* note 21, at 1499-1501.

²⁹Miller-Keane, *supra* note 3, at 1268.

³⁰Thibault, G. and W. Daley. "Cardiovascular Diseases" in Ramsey, P.G. and E.B. Larson (Eds.) Medical Therapeutics 1993 Philadelphia: Saunders, at 144.

³¹Lemmon, P.N., J. Kalman and K.Z. Sefcik. Tissue Plasminogen Activator 1994 14(12) Crit. Care Nurse 22, at 25.

large veins feeding directly into the heart. TPN is used to provide nutrition to patients with gastrointestinal pathology such as inflammation or obstruction.³²

Tube Feeding: This is a form of artificial hydration and nutrition (see supra) provided enterally by means of various types of tubes inserted into the gastro-intestinal tract.³³

Ventriculo-Peritoneal Shunt: This is a tube inserted into the cerebral ventricles to drain or shunt cerebrospinal fluid to the peritoneum or abdominal cavity³⁴ in order to prevent brain damage from hydrocephalus (excess fluid accumulation) due to trauma or congenital structural brain abnormalities.³⁵

³²Albers, D.H., W.F. Stenson and D.M. Bier (Eds.) Manual of Nutritional Therapeutics 1995 Boston: Little, Brown

³³Miller-Keane, supra note 3, at 1535.

³⁴Ibid., at 1363-1364.

³⁵Ibid., at 709.

APPENDIX B
EXAMPLES OF ADVANCE DIRECTIVES -
STRUCTURE AND FORMAT

EXAMPLE 1
PERSONAL HEALTH CARE DIRECTIVE

PERSONAL HEALTH CARE DIRECTIVE

I. INTRODUCTION

In this Directive I have stated my wishes for my own health care should the time ever come when I am not able to communicate because of illness or injury. This Directive should never be used if I am able to decide for myself. It must never be substituted for my judgment if I am competent to make these decisions.

If the time comes when I am unable to make these decisions, I would like this Directive to be followed and respected. In an emergency, please contact my advocate(s) or my family doctor, listed below. If these people are not available, then please do as I have requested in this Directive. Thank you.

I have thought about and discussed my decision with my family, friends and my family doctor. I do not want to leave these decisions to my family, my doctor or strangers who do not know me.

Dated this ___ day of _____, 19__.

SIGNED: _____
 Signature Print Name

 Health Insurance Number

II. ADVOCATE(S) and FAMILY PHYSICIAN

Advocate #1

Name	Address
Home Tel. #	Office Tel. #

Advocate #2

Name	Address
Home Tel. #	Office Tel. #

Physician

Name	Address
Home Tel. #	Office Tel. #

III. PERSONAL HEALTH CARE CHART

This chart is to be consulted only if I am no longer able to make or communicate my own decisions.

My choices are noted in the spaces provided below each section.

LIFE-THREATENING ILLNESS		FEEDING		CARDIAC ARREST	
If my condition is: REVERSIBLE IRREVERSIBLE		If my condition is: REVERSIBLE IRREVERSIBLE		If my condition is: REVERSIBLE IRREVERSIBLE	
↓	↓	↓	↓	↓	↓
Palliative Limited Surgical Intensive	Palliative Limited Surgical Intensive	Basic Supplemental Intravenous Tube	Basic Supplemental Intravenous Tube	No CPR CPR	No CPR CPR
<i>Date:</i> <i>Patient:</i> <i>Advocate #1:</i> <i>Advocate #2:</i> <i>Physician:</i>					
This document should be reviewed once a year, after an illness, or if there is any change in health. You can use the space below to show any changes in your Directive.					
<i>Date:</i> <i>Patient:</i> <i>Advocate #1:</i> <i>Advocate #2:</i> <i>Physician:</i>					
<i>Date:</i> <i>Patient:</i> <i>Advocate #1:</i> <i>Advocate #2:</i> <i>Physician:</i>					

IV. DEFINITIONS OF TERMS USED IN THE DIRECTIVE

Reversible Condition: Condition that may be cured without any remaining disability; e.g., pneumonia, bleeding ulcers.

Irreversible Condition: Condition that will leave lasting disabilities; e.g., multiple sclerosis, severe head injury, Alzheimer's disease.

Palliative Care

- keep me warm, dry, and pain free
- do not transfer to hospital unless absolutely necessary
- only give measures that enhance comfort or minimize pain; e.g., morphine for pain
- intravenous line started only if it improves comfort; e.g., for hydration
- no x-rays, blood tests or antibiotics unless they are given to improve comfort

Limited Care (includes Palliative)

- may or may not transfer to hospital
- intravenous therapy may be appropriate
- antibiotics should be used sparingly
- a trial of appropriate drugs may be used
- no invasive procedures; e.g., surgery
- do not transfer to Intensive Care Unit

Surgical Care (includes Limited)

- transfer to acute care hospital (where patient may be evaluated)
- emergency surgery if necessary
- do not admit to Intensive Care Unit
- do not ventilate (except during and after surgery); i.e., tube down throat and connected with machine

Intensive Care (includes Surgical)

- transfer to acute-care hospital without hesitation
- admit to Intensive Care Unit if necessary
- ventilate if necessary
- insert central line; i.e., main arteries for fluids when other veins collapse
- provide surgery, biopsies, all life-support systems and transplant surgery
- do everything possible to maintain life

Basic Feeding: Spoon feed with regular diet. Give all fluids by mouth that can be tolerated, but make no attempt to feed by special diets, intravenous fluids or tubes.

Supplemental Feeding: Give supplements or special diets, for example, high calorie, fat or protein supplements.

Intravenous Feeding: Give nutrients (water, salt, carbohydrate, protein and fat) by intravenous infusions.

Tube Feeding: Use tube feeding. There are two main types:

1. **Nasogastric Tube:** a soft plastic tube passed through the nose or mouth into the stomach.
2. **Gastrostomy Tube:** a soft plastic tube passed directly into stomach through the skin over the abdomen.

No CPR: Make no attempt to resuscitate.

CPR: Use cardiac massage with mouth-to-mouth breathing; may also include intravenous lines, electric shocks to the heart (defibrillators), tubes in throat to lungs (endotracheal tubes).

V. Personal Statement

I consider an irreversible condition to be any condition _____

I agree to the following procedures: (write Yes or No)

POST MORTEM _____ BLOOD TRANSFUSION _____

ORGAN DONATION _____ CREMATION _____

(Molloy and Mepham)

EXAMPLE 2

**UNIVERSITY OF TORONTO
CENTRE FOR BIOETHICS**

CENTRE FOR BIOETHICS LIVING WILL

INSTRUCTION DIRECTIVE

Directions: Refer back to "Health Situations" and "Life-Sustaining Treatments" for the definitions of terms used in this directive. Write your treatment decision (YES, NO, or UNDECIDED) in the boxes below for each combination of health situation and treatment. For example, if you want tube feeding in severe dementia you would write "yes" in the bottom right hand box. If you do not want tube feeding in severe dementia, you would write "no", and if you are undecided, you would write "undecided". On the other side of this page, under "further instructions", you may express in your own words the situations in which you would or would not want various life-sustaining treatments.

	CPR	RESPIRATOR	DIALYSIS	LIFE-SAVING SURGERY	BLOOD TRANSFUSION	LIFE-SAVING ANTIBIOTICS	TUBE FEEDING
CURRENT HEALTH							
PERMANENT COMA							
TERMINAL ILLNESS							
MILD STROKE							
MODERATE STROKE							
SEVERE STROKE							
MILD DEMENTIA							
MODERATE DEMENTIA							
SEVERE DEMENTIA							

PATIENT INFORMATION
 I have read and understood all sections of this living will. All previous living wills made by me are to be disregarded and this directive followed according to my wishes stated here.

Name: _____
 Address: _____
 Signature: _____
 Date: _____

WITNESS INFORMATION
 We have witnessed the signature above and have no reason to believe the person making this living will is incapable of making a living will.

WITNESS 1:
 Name: _____
 Address: _____
 Signature: _____

WITNESS 2:
 Name: _____
 Address: _____
 Signature: _____

HEALTH SITUATIONS:

In order to make an instruction directive, you need to imagine yourself becoming very ill or nearing death. It is not easy to imagine these situations or to decide upon treatments for them. To help you with this, we describe in detail some health situations in which a living will might be needed.

CURRENT HEALTH:

This describes the way your health is now.

PERMANENT COMA:

This means you would be permanently unconscious. Permanent coma is usually caused by decreased blood flow to the brain, for example, from the heart stopping. You would be unable to eat or drink and would need a feeding tube for nourishment. You would not have bowel or bladder control. You would need to be in bed and you would never regain consciousness. You could live at home with someone caring for you all day and night; otherwise you would probably need to be cared for in a chronic care hospital.

TERMINAL ILLNESS:

This means you would have an illness for which there is no known cure, such as some types of cancer. It is likely that you would die within six months even if you received treatment.

STROKE:

This means you would have damage to the brain causing permanent physical disability such as paralysis. You might also have trouble communicating because of impaired speech. These problems stay the same for the rest of your life. They do not get worse with time unless there is another injury to the brain, such as another stroke. Stroke can be described as:

● **Mild:** You would have mild paralysis on one side of the body. You could walk with a cane or walker. You would be able to have meaningful conversations, but might have trouble finding words. You could carry out most routine daily activities, such as work and household duties, dressing, eating, bathing, and using the toilet. You would have bowel and bladder control. You could live at home with someone caring for you for a few hours each day.

● **Moderate:** You would have moderate paralysis on one side of the body. You would be unable to walk and would need a wheelchair. You could carry out conversations, but you might not always make sense. You would need help with routine daily activities. You may have bowel and bladder control. You could live at home with someone caring for you throughout the daytime; otherwise you would probably need to live in a nursing home.

● **Severe:** You would have severe paralysis on one side of the body. You would be unable to walk, and would need to be in a chair or bed. You would not have meaningful conversations. You would be unable to carry out routine daily activities. You would need a feeding tube for nourishment. You would not have bowel or bladder control. You could live at home with someone caring for you all day and night; otherwise you would probably need to be cared for in a chronic care hospital.

DEMENTIA:

This means you would have a progressive and irreversible deterioration in brain function. You would be awake and aware but you would have trouble thinking clearly, recognizing people, and communicating. The most common cause of dementia is Alzheimer's disease. Dementia gradually gets worse over months or years. Dementia can be described as:

● **Mild:** You could have meaningful conversations, but would be forgetful and have poor short term memory. You could carry out most routine daily activities, such as work and household duties, dressing, eating, bathing, and using the toilet. You would have bowel and bladder control. You could live at home with someone caring for you for a few hours each day.

● **Moderate:** You would not always recognize family and friends. You could carry out conversations but you might not always make sense. You would need help with routine daily activities. You may have bowel and bladder control. You could live at home with someone caring for you throughout the daytime; otherwise you would probably need to live in a nursing home.

● **Severe:** You would not recognize family and friends, and would be unable to have meaningful conversations. You would be unable to carry out routine daily activities. You would need a feeding tube for nourishment. You would not have bowel and bladder control. You could live at home with someone caring for you all day and night; otherwise you would probably need to be cared for in a chronic care hospital.

LIFE-SUSTAINING TREATMENTS:

In each of the health situations described above, you might need one or more of the following life-sustaining treatments.

CARDIOPULMONARY RESUSCITATION (CPR) is used to try to restart the heart if it has stopped beating. CPR involves applying pressure and electrical shocks to the chest, assisted breathing with a respirator (breathing machine) through a tube inserted down the throat and into the lungs, and giving drugs through a needle into a vein. It is usually followed by unconsciousness and several days of treatment in an intensive care unit. Without CPR, immediate death is certain. On average when hospitalized patients are given CPR, it is successful at restarting the heart in about 41% of patients (41 patients out of 100). However, about 14% (14 patients out of 100) will live to be discharged from hospital. Patients whose hearts are successfully restarted but who do not survive to hospital discharge spend several days in an intensive care unit before death. The chance that a person will live depends on the cause of the heart stopping and the seriousness of the person's other illnesses.

RESPIRATOR (breathing machine) is used when a person cannot breathe; for example, because of emphysema or a serious pneumonia. A tube is put down the person's throat into the lungs. The respirator is needed as long as the person's lungs are not working. Without the respirator, a person with respiratory failure will probably die within minutes to hours. With the respirator, the chance that a person will live depends on the cause of the respiratory failure, and the seriousness of the person's other illnesses.

DIALYSIS (kidney machine) replaces the normal functions of the kidney. Dialysis removes excess potassium, water, and other waste products from the blood. Without dialysis, the potassium in the blood would build up and cause the heart to stop. Dialysis is needed as long as the person's kidneys are not working. Without dialysis, a person with kidney failure will die within 7 to 14 days. With dialysis, the chance that a person will live depends on the cause of the kidney failure and the seriousness of the person's other illnesses.

LIFE-SAVING SURGERY may involve a wide range of procedures, for example, removal of an inflamed gall bladder or appendix. Without surgery, a person with a serious illness may die within hours to days. With surgery, the chance that a person will live depends on why the person needed surgery and the seriousness of the person's other injuries or illnesses.

BLOOD TRANSFUSION refers to blood given through a needle inserted in a person's vein. A person who is bleeding very heavily from a car accident, a stomach ulcer, or during major surgery, needs a blood transfusion. Without a blood transfusion, a person who is bleeding very heavily will probably die within hours. With a blood transfusion, the chance that a person will live depends on the seriousness of the person's other injuries or illnesses.

LIFE-SAVING ANTIBIOTICS refers to the drugs needed to treat life-threatening infections; for example, pneumonia or meningitis. These drugs usually are given through a needle inserted in a person's vein. Without antibiotics, a person with a life-threatening infection will likely die in hours to days. With antibiotics, the chance that a person will live depends on the seriousness of the infection and the seriousness of the person's other illnesses.

TUBE FEEDING involves putting a tube into a person's stomach (through the nose, or through a small hole in the abdomen). A person who cannot eat (e.g., someone in a coma) needs a feeding tube. Tube feeding is needed as long as the person cannot eat. Without tube feeding, a person who cannot eat or drink will die within days to weeks. With tube feeding, the chance that a person will live depends on the seriousness of the person's other injuries or illnesses.

EXAMPLE 3
VALUES HISTORY

SECTION 1

A. WRITTEN LEGAL DOCUMENTS

Have you written any of the following legal documents? _____

If so, please complete the requested information.

Living Will

Date written: _____

Document location: _____

Comments: (e.g., any limitations, special requests, etc.) _____

Durable Power of Attorney

Date written: _____

Document location: _____

Comments: (e.g., whom have you named to be your decision maker?) _____

Durable Power of Attorney for Health Care Decisions

Date written: _____

Document location: _____

Comments: (e.g., whom have you named to be your decision maker?) _____

Organ Donations

Date written: _____

Document location: _____

Comments: (e.g., any limitations on which organs you would like to donate?) _____

B. WISHES CONCERNING SPECIFIC MEDICAL PROCEDURES

If you have ever expressed your wishes, either written or orally, concerning any of the following medical procedures, please complete the requested information. If you have not previously indicated your wishes on these procedures and would like to do so now, please complete this information.

Organ Donation

To whom expressed: _____

If oral, when? _____

If written, when? _____

Document location: _____

Comments: _____

Kidney Dialysis

To whom expressed: _____

If oral, when? _____

If written, when? _____

Document location: _____

Comments: _____

Cardiopulmonary Resuscitation (CPR)

To whom expressed: _____

If oral, when? _____

If written, when? _____

Document location: _____

Comments: _____

Respirators

To whom expressed: _____

If oral, when? _____

If written, when? _____

Document location: _____

Comments: _____

Artificial Nutrition

To whom expressed: _____

If oral, when? _____

If written, when? _____

Document location: _____

Comments: _____

Artificial hydration

To whom expressed: _____

If oral, when? _____

If written, when? _____

Document location: _____

Comments: _____

C. GENERAL COMMENTS

Do you wish to make any general comments about the information you provided in this section? _____

SECTION 2

A. YOUR OVERALL ATTITUDE TOWARD YOUR HEALTH

1. How would you describe your current health status? If you currently have any medical problems, how would you describe them? _____

2. If you have current medical problems, in what ways, if any, do they affect your ability to function? _____

3. How do you feel about your current health status? _____

4. How well are you able to meet the basic necessities of life--eating, food preparation, sleeping, personal hygiene, etc.? _____

5. Do you wish to make any general comments about your overall health? _____

B. YOUR PERCEPTION OF THE ROLE OF YOUR DOCTOR AND OTHER HEALTH CAREGIVERS

1. Do you like your doctors? _____

2. Do you trust your doctors? _____

3. Do you think your doctors should make the final decision concerning any treatment you might need? _____

4. How do you relate to your caregivers, including nurses, therapists, chaplains, social workers, etc.? _____

5. Do you wish to make any general comments about your doctor and other health caregivers? _____

C. YOUR THOUGHTS ABOUT INDEPENDENCE AND CONTROL

1. How important is independence and self-sufficiency in your life? _____

2. If you were to experience decreased physical and mental abilities, how would that affect your attitude toward independence and self-sufficiency? _____

3. Do you wish to make any general comments about the value of independence and control in your life? _____

D. YOUR PERSONAL RELATIONSHIPS

1. Do you expect that your friends, family and/or others will support your decisions regarding medical treatment you may need now or in the future? _____

2. Have you made any arrangements for your family or friends to make medical treatment decisions on your behalf? If so, who has agreed to make decisions for you and in what circumstances? _____

3. What, if any, unfinished business from the past are you concerned about (e.g., personal and family relationships, business and legal matters)? _____

4. What role do your friends and family play in your life? _____

5. Do you wish to make any general comments about the personal relationships in your life? _____

E. YOUR OVERALL ATTITUDE TOWARD LIFE

1. What activities do you enjoy (e.g., hobbies, watching TV, etc.)? _____

2. Are you happy to be alive? _____

3. Do you feel that life is worth living? _____

4. How satisfied are you with what you have achieved in your life? _____

5. What makes you laugh/cry? _____

6. What do you fear most? What frightens or upsets you? _____

7. What goals do you have for the future? _____

8. Do you wish to make any general comments about your attitude toward life? _____

F. YOUR ATTITUDE TOWARD ILLNESS, DYING, AND DEATH

1. What will be important to you when you are dying (e.g., physical comfort, no pain, family members present, etc.)? _____

2. Where would you prefer to die? _____

3. What is your attitude toward death? _____

4. How do you feel about the use of life-sustaining measures in the face of terminal illness? _____

permanent coma? _____

irreversible chronic illness (e.g., Alzheimer's disease)? _____

5. Do you wish to make any general comments about your attitude toward illness, dying, and death? _____

G. YOUR RELIGIOUS BACKGROUND AND BELIEFS

1. What is your religious background? _____

2. How do your religious beliefs affect your attitude toward serious or terminal illness? _____

3. Does your attitude toward death find support in your religion? _____

4. How does your faith community, church or synagogue view the role of prayer or religious sacraments in an illness? _____

5. Do you wish to make any general comments about your religious background and beliefs? _____

H. YOUR LIVING ENVIRONMENT

1. What has been your living situation over the last 10 years (e.g., lived alone, lived with others, etc.)? _____

2. How difficult is it for you to maintain the kind of environment for yourself that you find comfortable? Does any illness or medical problem you have now mean that it will be harder in the future? _____

3. Do you wish to make any general comments about your living environment? _____

I. YOUR ATTITUDE CONCERNING FINANCES

1. How much do you worry about having enough money to provide for your care? _____

2. Would you prefer to spend less money on your care so that more money can be saved for the benefit of your relatives and/or friends? _____

3. Do you wish to make any general comments concerning your finances and the cost of health care? _____

J. YOUR WISHES CONCERNING YOUR FUNERAL

1. What are your wishes concerning your funeral and burial or cremation? _____

2. Have you made your funeral arrangements? If so, with whom? _____

3. Do you wish to make any general comments about how you would like your funeral and burial or cremation to be arranged or conducted? _____

APPENDIX C
STUDY QUESTIONNAIRES

HEALTH CARE PROFESSIONALS

1. I think people want to have more control over decisions concerning their health.
2. It is desirable that people have more control over such decisions.
3. Patients should have control over the following types of decisions:
 - (i) aggressive treatment
 - (ii) cardio-pulmonary resuscitation
 - (iii) life-prolonging, non-aggressive treatment
4.
 - (a) I am in favour of people making health care directives or living wills indicating what medical treatments they would accept and what treatments they would refuse in the event they should become incompetent.
 - (b) Such a directive is legally binding and must be followed by health care professionals.
5. If a health care professional refused to follow a patient's living will, there would be legal consequences.
6.
 - (a) I am aware of new legislation that will legalize living wills.
 - (b) I became aware of it through:
 - Health care professional organization
 - My employer
 - Media
 - Other (please specify)
 - (c) I had input into the drafting of this legislation.
 - (d) I think I should have had some input.
 - (e) I am in favour of this legislation.
7. (a) I am familiar with the following terms and what they mean:
 - (i) living will
 - (ii) advance health care directive
 - (iii) durable power of attorney
8. I think that most people are sufficiently well informed with respect to medical technology to be in a position to make informed advance health directives or living wills.

9. There are occasions when it is necessary and appropriate to treat people against their will.
10. Health care institutions should have formal policies with respect to living wills so that all patients admitted to the facility are asked whether or not they have a living will.
11. The onus should be on the patient to inform health care professionals as to whether or not they have a living will.
12. Who should decide whether a treatment decision is in the patient's best interests:
 - (i) the patient
 - (ii) the patient's family
 - (iii) the medical team
13. I consider tube feeding to be:
 - (a) a medical treatment
 - (b) a comfort care measure
14. Written living wills are legally binding.
15. Oral, unwritten living wills are legally binding.
16. Anyone should be able to make a living will and it should be followed by health care professionals. (If no, answer Question 17. If yes, do not answer Question 17.)
17. Living wills should be made only in specific circumstances, such as:
 - (i) terminally ill patients
 - (ii) patients with chronic but not terminal illnesses such as multiple sclerosis
 - (iii) patients with permanent disabilities due to trauma or illness (eg, quadriplegics, ALS)
 - (iv) patients with genetic abnormalities which do not become apparent until adult life (eg, Huntington's disease)
18. A person has not drafted a formal living will but has made a public statement in this regard. I think this is legally binding and should be followed.
19. I think a living will should be followed only if the patient's condition is terminal and irreversible.
20. I think a patient's living will to withhold treatment should be followed even where complete recovery is likely if the treatment were given.

21. I think that a patient's age should be taken into consideration when deciding whether or not to follow a living will.
22. Living wills for treatment withdrawal should be followed.
23. Living wills instructing health care professionals to continue treatment that is futile should be followed.
24. Health care professionals should have the discretion to override advance health care directives if they feel that this is in the best interests of the patient.
25. Discussion of living wills would bring about more adversarial relationships between patients and health care professionals.
26. I would feel comfortable following a patient's living will that simply stated "No heroic measures."
27. I would feel comfortable following a patient's living will that set out specific treatment decisions.
28. The shock and trauma associated with severe, acute injuries renders a person mentally incompetent to make treatment decisions that are in their best interests.
29. The severe pain and trauma associated with a myocardial infarction renders a person mentally incompetent to make treatment decisions that are in their best interests.
30. I would feel comfortable in following a patient's living will to withhold tube feeding.
31. I would be reluctant to follow a patient's living will to withhold treatment because the patient may have changed his mind between the time of the making of the will and the time of the treatment decision.
32. I would be reluctant to follow a patient's living will where I disagreed with the patient's treatment decision.
33. A fit, healthy 45-year-old man has a living will stating that he wishes not to be resuscitated in the event of a myocardial infarction. I would feel comfortable following this.

34. You are having coffee with a health care professional colleague when she tells you emphatically that she would not wish to be resuscitated under any circumstances. She is 30 years old and has no health problems. Two days later, she has a cardiac arrest while at work. You are present when the cardiac arrest occurs.
- (a) Would you feel comfortable following her directive not to resuscitate?
 - (b) Would your decision be different if you knew your colleague suffered from a terminal illness such as cancer?
35. A 45-year-old man with Huntington's Disease has a living will stating that he does not want tube feedings or IV therapy if his condition deteriorates and he is unable to make that decision at that time. I would feel comfortable following this.
36. A 40-year-old patient with a myocardial infarction has a living will directing the refusal of drugs such as Streptokinase. I would feel comfortable following this.
37. A 20-year-old woman has a living will stating that in the event of an acute traumatic event such as a motor vehicle accident that rendered her comatose, she does not want to be intubated and maintained on mechanical ventilation. I would feel comfortable following this.
38. A 20-year-old woman has a living will stating that in the event of an acute traumatic event such as a motor vehicle accident that rendered her comatose, she wishes to be intubated and maintained on mechanical ventilation but that if there was no improvement in her condition after one week, she wishes to be taken off the ventilator. I would feel comfortable following this.
39. A 20-year-old woman has a living will stating that in the event of an acute traumatic event such as a motor vehicle accident that rendered her comatose, she does not want tube feedings or IV therapy. I would feel comfortable following this.
40. A health care professional should have the discretion to override a patient's living will if the professional thinks that the patient lacked sufficient understanding of the proposed treatment at the time the directive was made.
41. A psychiatric patient has a written directive (made at a time when he was mentally competent and not psychotic) stating that specific psychotropic drugs are not to be administered to him under any circumstances including an acute psychotic episode.
- (a) I would feel comfortable following this.
 - (b) I think that this directive is legally binding.

42. A 35-year-old alcoholic with a history of duodenal ulcers has a living will (made at a time when he was mentally competent and sober) stating: "Life is one big party. If I can't party, I don't want to live. I don't want to lay in any hospital bed with a bunch of tubes in me and I don't want any blood transfusions under any circumstances even if I would die without it." He has developed an acute upper GI bleed as a result of a weekend binge. It is the medical team's opinion that transfusion therapy is necessary to save his life.
- (a) I would feel comfortable following this.
 - (b) I think this document is legally binding.
43. (a) I think that following a patient's living will with a refusal of treatment that is likely to be 100% successful is equivalent to assisting the person to commit suicide.
- (b) I think that health care team members could be held criminally liable for following such a directive.
 - (c) I think that health care team members could be successfully sued by the person who executed the advance directive if the directive is not followed.
44. A patient has a living will stating: "I hereby instruct my physicians to do whatever is necessary to alleviate my pain and suffering, even if this means giving me a dose of medication that is so strong that I will not survive."
- (a) I would feel comfortable following this.
 - (b) I think this document is legally binding.
45. The expertise of health care professionals gives them greater authority than patients with respect to treatment decisions.
46. The following treatments constitute "extraordinary measures":
- Agree Disagree
- CPR
 - Mechanical ventilation
 - Intubation
 - IV therapy
 - Tube feeding (NG, gastrostomy)
 - Chemotherapy
 - Radiotherapy
 - Dialysis
 - VP shunts
 - Thrombolytic therapy to treat MI
(Streptokinase, TPA)
 - Blood transfusions

Analgesic administration by
 IV infusion pump
 TPN
 Invasive diagnostic procedures
 (eg, angiograms, endoscopies)
 Non-invasive diagnostic
 procedures (eg, ultrasound)

47. In an emergency situation, the medical team has the authority to administer any treatments they deem to be appropriate despite any prior expressed wishes of the patient.
48. Sometimes patients are experiencing so much trauma and stress that they are unable to make rational decisions with respect to their health care. It is appropriate for the medical team to "take over" and make the decisions for the patient in these circumstances.
49. The right of a patient to extraordinary medical treatment should be balanced against other factors, such as the likelihood of a successful treatment outcome and the availability of scarce medical resources.
50. (a) I have cared for a patient who had a living will.
 (b) I felt comfortable following the patient's expressed wishes.
51. (a) Do you have a living will for yourself?
 (b) If yes, what provisions does it contain?
 (c) If no, have you considered drafting such a document?
 (d) If yes, what provisions would you include?
52. What is your area of practice?
 M.D.
 R.N.
 Other (please specify)

Clinical area: (circle)

Medicine	Surgery	Emergency	Intensive Care
Coronary Care	Pediatrics	Psychiatry	Geriatrics
Other (please specify)			

EMERGENCY MEDICAL SERVICES PERSONNEL

1. I think people want to have more control over decisions concerning their health.
2. It is desirable that people have more control over such decisions.
3. People should have control over the following types of decisions:
 - (i) aggressive treatment
 - (ii) cardio-pulmonary resuscitation
 - (iii) life-prolonging, non-aggressive treatment
4.
 - (a) I am in favour of people making health care directives or living wills indicating what medical treatments they would accept and what treatments they would refuse in the event they should become incompetent.
 - (b) Such a directive is legally binding and must be followed by health care professionals.
5. If a health care professional refused to follow a patient's living will, there would be legal consequences.
6.
 - (a) I am aware of new legislation that will legalize living wills.
 - (b) I became aware of it through:
 - Health care professional organization
 - My employer
 - Media
 - Other (please specify)
 - (c) I had input into the drafting of this legislation.
 - (d) I think I should have had some input.
 - (e) I am in favour of this legislation.
7.
 - (a) I am familiar with the following terms and what they mean:
 - (i) living will
 - (ii) advance health care directive
 - (iii) durable power of attorney
8. I think that most people are sufficiently well informed with respect to medical technology to be in a position to make informed advance health directives or living wills.

9. There are occasions when it is necessary and appropriate to treat people against their will.
10. Health care institutions should have formal policies with respect to living wills so that all patients admitted to the facility are asked whether or not they have a living will.
11. The onus should be on the patient to inform health care professionals as to whether or not they have a living will.
12. Who should decide whether a treatment decision is in the patient's best interests:
 - (i) the patient
 - (ii) the patient's family
 - (iii) the medical team
13. I think it is appropriate for emergency medical services to honour valid living wills in the pre-hospital setting.
14. Written living wills are legally binding.
15. Oral, unwritten living wills are legally binding.
16. Anyone should be able to make a living will and it should be followed by health care professionals. (If no, answer Question 17. If yes, do not answer Question 17.)
17. Living wills should be made only in specific circumstances, such as:
 - (i) terminally ill patients
 - (ii) patients with chronic but not terminal illnesses such as multiple sclerosis
 - (iii) patients with permanent disabilities due to trauma or illness (eg, quadriplegics, ALS)
 - (iv) patients with genetic abnormalities which do not become apparent until adult life (eg, Huntington's disease)
18. A person has not drafted a formal living will but has made a public statement in this regard. I think this is legally binding and should be followed.
19. I think a living will should be followed only if the patient's condition is terminal and irreversible.

20. I think a patient's living will to withhold treatment should be followed even where complete recovery is likely if the treatment were given.
21. I think that a patient's age should be taken into consideration when deciding whether or not to follow a living will.
22. Living wills for treatment withdrawal should be followed.
23. Living wills instructing health care professionals to continue treatment that is futile should be followed.
24. Health care professionals should have the discretion to override advance health care directives if they feel that this is in the best interests of the patient.
25. Emergency medical services must take patient preferences into account before implementing resuscitative efforts.
26. I would feel comfortable following a patient's living will that simply stated "No heroic measures".
27. I would feel comfortable following a patient's living will that set out specific treatment decisions.
8. The shock and trauma associated with severe, acute injuries renders a person mentally incompetent to make treatment decisions that are in their best interests.
29. The severe pain and trauma associated with a myocardial infarction renders a person mentally incompetent to make treatment decisions that are in their best interests.
30. Discussion of living wills would bring about more adversarial relationships between patients and health care professionals.
31. I would be reluctant to follow a patient's living will to withhold treatment because the patient may have changed his mind between the time of the making of the will and the time of the treatment decision.
32. I would be reluctant to follow a patient's living will where I disagreed with the patient's treatment decision.
33. A fit, healthy 45-year-old man has a living will stating that he wishes not to be resuscitated in the event of a myocardial infarction. He collapses at work and you are the first responder. You find him unconscious. His living will is presented to you before you have begun CPR. Would you feel comfortable following this?

34. You are having coffee with a health care professional colleague when she tells you emphatically that she would not wish to be resuscitated under any circumstances. She is 30 years old and has no health problems. Two days later, she has a cardiac arrest while at work. You are present when the cardiac arrest occurs.
- (a) Would you feel comfortable following her directive not to resuscitate?
 - (b) Would your decision be different if you knew your colleague suffered from a terminal illness such as cancer?
35. A 45-year-old man with Huntington's Disease has a living will stating that he does not wish to be resuscitated under any circumstances. He is in the early stages of Huntington's and still working and functioning fairly independently when he collapses at work. You are the first responder. You find him unconscious. His living will is presented to you before you have begun CPR. Would you feel comfortable following this?
36. A 40-year-old patient with a myocardial infarction has a living will directing the refusal of drugs such as Streptokinase. He collapses at a shopping centre and is unconscious when you arrive at the scene as first responder. His wife tells you that just before he collapsed, he said: "Don't even bother taking me to a hospital because I don't want any drugs or tubes. If it's my time, just let me go peacefully." Would you feel comfortable following this?
37. A 20-year-old woman has a living will stating that in the event of an acute traumatic event such as a motor vehicle accident that rendered her comatose, she does not want to be intubated and maintained on mechanical ventilation and, in fact, does not wish any resuscitative efforts whatsoever. She is involved in an MVA and appears to have sustained a C-spine fracture. You arrive at the scene as first responder. Would you feel comfortable following this?
38. A 19-year-old woman has a living will stating "no intubation". She has had severe asthma since childhood. She has a severe asthmatic attack while out shopping and 911 is called. You are the first responder. When you arrive at the scene, she is still able to talk and she tells you that she does not want to go to hospital and gives you her living will. She then loses consciousness. Would you feel comfortable following this?
39. Emergency medical services should have explicit protocols for advance directives or living wills.
40. A health care professional should have the discretion to override a patient's living will if the professional thinks that the patient lacked sufficient understanding of the proposed treatment at the time the directive was made.

41. A psychiatric patient has a directive (made at a time when he was mentally competent and not psychotic) stating that specific psychotropic drugs are not to be administered to him under any circumstances including an acute psychotic episode and he does not wish to be transported to a hospital where such drugs would be administered.
- (a) I would feel comfortable following this.
 - (b) I think that this directive is legally binding.
42. A 35-year-old alcoholic with a history of duodenal ulcers has a living will (made at a time when he was mentally competent and sober) stating: "Life is one big party. If I can't party, I don't want to live. I don't want to lay in any hospital bed with a bunch of tubes in me and I don't want any blood transfusions under any circumstances even if I would die without it. Don't even take me to a hospital." He has an acute upper GI bleed while in the local bar on a weekend binge. He collapses and the bartender calls 911. You are the first responder.
- (a) I would feel comfortable following this.
 - (b) I think this document is legally binding.
43. (a) I think that following a patient's living will with a refusal of treatment that is likely to be 100% successful is equivalent to assisting the person to commit suicide.
- (b) I think that health care team members could be held criminally liable for following such a directive.
 - (c) I think that health care team members could be successfully sued by the person who executed the advance directive if the directive is not followed.
44. A patient has a living will stating: "I hereby instruct my physicians to do whatever is necessary to alleviate my pain and suffering, even if this means giving me a dose of medication that is so strong that I will not survive."
- (a) I would feel comfortable following this.
 - (b) I think this document is legally binding.
45. The expertise of health care professionals gives them greater authority than patients with respect to treatment decisions.
46. The following treatments constitute "extraordinary measures":
- Agree Disagree
- CPR
 Mechanical ventilation
 Intubation
 IV therapy

Tube feeding (NG, gastrostomy)
Chemotherapy
Radiotherapy
Dialysis
VP shunts
Thrombolytic therapy to treat MI
(Streptokinase, TPA)
Blood transfusions
Analgesic administration by
IV infusion pump
TPN
Invasive diagnostic procedures
(eg, angiograms, endoscopies)
Non-invasive diagnostic
procedures (eg, ultrasound)

47. In an emergency situation, the medical team has the authority to administer any treatments they deem to be appropriate despite any prior expressed wishes of the patient.
48. Sometimes patients are experiencing so much trauma and stress that they are unable to make rational decisions with respect to their health care. It is appropriate for the medical team to "take over" and make the decisions for the patient in these circumstances.
49. The right of a patient to extraordinary medical treatment should be balanced against other factors, such as the likelihood of a successful treatment outcome and the availability of scarce medical resources.
50.
 - (a) I have cared for a patient who had a living will.
 - (b) I felt comfortable following the patient's expressed wishes.
51.
 - (a) Do you have a living will for yourself?
 - (b) If yes, what provisions does it contain?
 - (c) If no, have you considered drafting such a document?
 - (d) If yes, what provisions would you include?

LAWYERS

1. I think people want to have more control over decisions concerning their health.
2. It is desirable that people have more control over such decisions.
3. People should have control over the following types of decisions:
 - (i) aggressive treatment
 - (ii) cardio-pulmonary resuscitation
 - (iii) life-prolonging, non-aggressive treatment
4. I am in favour of people making health care directives or living wills indicating what medical treatments they would accept and what treatments they would refuse in the event they should become incompetent.
5. I think that most people are sufficiently well informed with respect to medical technology to be in a position to make informed advance health directives or living wills.
6. There are occasions when it is necessary and appropriate to treat people against their will.
7. Health care institutions should have formal policies with respect to living wills so that all patients admitted to the facility are asked whether or not they have a living will.
8. Who should decide whether a treatment decision is in the patient's best interests:
 - (i) the patient
 - (ii) the patient's family
 - (iii) the medical team
9. Anyone should be able to make a living will and it should be followed by health care professionals. (If no, answer Question 10. If yes, do not answer Question 10.)
10. Living wills should be made only in specific circumstances, such as:
 - (i) terminally ill patients
 - (ii) patients with chronic but not terminal illnesses such as multiple sclerosis
 - (iii) patients with permanent disabilities due to trauma or illness (eg, quadriplegics, ALS)

- (iv) patients with genetic abnormalities which do not become apparent until adult life (eg, Huntington's disease)
- 11. The onus should be on the patient to inform health care professionals as to whether or not they have a living will.
- 12. I think a living will should be followed only if the patient's condition is terminal and irreversible.
- 13. I think a patient's living will to withhold treatment should be followed even where complete recovery is likely if the treatment were given.
- 14. I think that a patient's age should be taken into consideration when deciding whether or not to follow a living will.
- 15. Living wills instructing health care professionals to continue treatment that is futile should be followed.
- 16. Living wills for treatment withdrawal should be followed.
- 17. Health care professionals should have the discretion to override advance health care directives if they feel that this is in the best interests of the patient.
- 18. A person has not drafted a formal living will but has made a public statement in this regard. I think this is legally binding and should be followed.
- 19. Discussion of living wills would bring about more adversarial relationships between patients and health care professionals.
- 20. The shock and trauma associated with severe, acute injuries renders a person mentally incompetent to make treatment decisions that are in their best interests.
- 21. The severe pain and trauma associated with a heart attack renders a person mentally incompetent to make treatment decisions that are in their best interests.
- 22. Health care professionals ought to have the discretion not to follow a patient's living will to withhold treatment because they believe that the patient may have changed his mind between the time of the making of the will and the time of the treatment decision.
- 23. A person's living will to withhold tube feeding should be followed by health care professionals.
- 24. Health care professionals ought to have the discretion not to follow a patient's living will where they disagree with the patient's treatment choice.

25. A 20-year-old woman asks you to draft a living will stating that in the event of an acute traumatic event such as a motor vehicle accident that rendered her comatose, she does not wish to receive non-aggressive, life-prolonging therapies such as artificial hydration and nutrition (intravenous therapy and tube feeding). Would you feel comfortable drafting this will?
26. A 20-year-old woman asks you to draft a living will stating that in the event of an acute traumatic event such as a motor vehicle accident that rendered her comatose, she does not wish to receive aggressive medical intervention (for example, she does not want to be put on a respirator). Would you feel comfortable drafting this will?
27. A fit, healthy 45-year-old man asks you to draft a living will stating that he wishes not to be resuscitated if he has a heart attack. Would you feel comfortable drafting this will?
28. A 45-year-old man with Huntington's Disease (a genetic disorder that does not become apparent until middle age and causes severe neurological damage) asks you to draft a living will stating that he does not want tube feedings or intravenous therapy if his condition deteriorates and he is unable to make that decision at that time. Would you feel comfortable drafting this will?
29. A healthy, fit 40-year-old man asks you to draft a living will stating that he does not want to receive a drug called Streptokinase. This drug is routinely given for the treatment of heart attacks and usually has a very high success rate. Would you feel comfortable drafting this will?
30. A health care professional ought to have the discretion to override a patient's living will if the professional thinks that the patient lacked sufficient understanding of the proposed treatment at the time the directive was made.
31. A psychiatric patient asks you to draft a health care directive stating that specific anti-psychotic drugs are not to be administered to him under any circumstances including an acute psychotic episode. He is mentally competent when he asks you to draft the directive. Would you feel comfortable drafting this directive?
32. A 35-year-old alcoholic asks you to draft a living will stating: "Life is one big party. If I can't party, I don't want to live. I don't want to lay in any hospital bed with a bunch of tubes in me and I don't want any blood transfusions under any circumstances even if I would die without it." He has a history of bleeding stomach ulcers (due to his alcoholism) which can be fatal but which can be successfully treated by blood transfusions. Would you feel comfortable drafting this will?

33. (a) I think that following a patient's living will with a refusal of treatment that is likely to be 100% successful is equivalent to assisting the person to commit suicide.
- (b) I think that health care team members could be held criminally liable for following such a directive.
- (c) I think that health care team members could be successfully sued by the person who executed the advance directive if the directive is not followed.
34. A person asks you to draft a living will stating: "I hereby instruct my physicians to do whatever is necessary to alleviate my pain and suffering, even if this means giving me a dose of medication that is so strong that I will not survive." Would you feel comfortable drafting this will?
35. The expertise of health care professionals gives them greater authority than patients with respect to treatment decisions.
36. In an emergency situation, the medical team has the authority to administer any treatments they deem to be appropriate despite any prior expressed wishes of the patient.
37. Sometimes patients are experiencing so much trauma and stress that they are unable to make rational decisions with respect to their health care. It is appropriate for the medical team to "take over" and make the decisions for the patient in these circumstances.
38. The right of a patient to extraordinary medical treatment should be balanced against other factors, such as the likelihood of a successful treatment outcome and the availability of scarce medical resources.
39. Have you ever represented a client who had an advance health care directive and the issue arose as to whether this directive should be followed or not?
40. You are having coffee with a colleague when she tells you emphatically that she would not wish to be resuscitated under any circumstances. She is 30 years old and has no health problems. Two days later, she has collapses while at work. You are present when this occurs.
- a) Would you advise the emergency medical services of your colleague's wish?
- (b) Would your decision be different if you knew she suffered from a terminal illness such as cancer?
41. A client asks you to draft a living will that simply states "No heroic measures"? Would you feel comfortable drafting this will?

42. (a) Do you have a living will for yourself?
- (b) If yes, what provisions does it contain?
- (c) If no, have you considered drafting such a document?
- (d) If yes, what provisions would you include?

APPENDIX D
CATEGORIES OF SURVEY QUESTIONS

H = Health Care Professionals Quantitative Questionnaire
E = Emergency Medical Services Personnel Questionnaire
L = Lawyers Questionnaire

Medical Technology

H: 13, 46

Legal Status of Advance Directives

H: 4b, 5-7, 10, 14, 15, 18, 47

E: 4b, 5-7, 10, 14, 15, 18, 25, 39, 43, 47

L: 11, 18, 33, 36

Institutional Policy Formulation

H: 11

E: 11

Relevant Bioethical Concepts

A. Autonomy

H: 1, 2, 3, 4a, 8, 9, 12, 16, 17, 19-25, 32, 40, 45, 47-49

E: 1, 2, 3, 4a, 8, 9, 12, 16, 17, 19-24, 30, 32, 40, 45, 48, 49

L: 1, 2, 3, 5, 6, 8-10, 12-17, 19, 24, 30, 35, 37, 38

Futility and the Right to Demand Non-Beneficial Treatment

H: 23

E: 23

L: 15

B. Decisional Competency

H: 28, 39, 31

E: 28, 29, 31

L: 20, 21, 22

C. Resource Allocation

H: 49

E: 49

Hypothetical Treatment Scenarios

- a. **Vague v. Specific Wording**
 - H: 26, 27
 - E: 26, 27
 - L: 41

- b. **Withholding v. Withdrawing Treatment**
 - H: 20, 22
 - E: 20, 22
 - L: 13, 16

- c. **High Technology v. Low Technology**
 - H: 30, 37, 38, 39
 - L: 23, 25, 26

- d. **Acute v. Chronic Illness**
 - H: 35
 - E: 35
 - L: 28

- e. **"Irrational" Treatment Choices**
 - H: 33, 34, 36, 37, 42
 - E: 33-38, 42
 - L: 27, 29, 32, 40

- f. **Psychiatric Treatment Issues**
 - H: 41
 - L: 31

- g. **Euthanasia**
 - H: 44
 - E: 44
 - L: 34

Clinical and Personal Experiences

- H: 50-52
- E: 50, 51
- L: 39, 42

APPENDIX E
COMPARATIVE QUANTITATIVE
ANALYSIS

TABLE 1
Extraordinary Treatment
 (% of "yes" responses)

H = Health Care Professionals

E = Emergency Medical Services Personnel

TREATMENT	H	E
Cardiopulmonary Resuscitation (CPR)	61	61
Mechanical Ventilation	66	68
Intubation	61	48
Intravenous Therapy	60	26
Tube Feeding	14	55
Chemotherapy	42	65
Radiotherapy	41	65
Dialysis	47	68
Ventriculo-Peritoneal Shunts	46	55
Tissue Plasminogen Activator (TPA)	24	52
Blood Transfusions	23	45
Morphine Intravenous Infusion Therapy	15	19
Total Parenteral Nutrition (TPN)	38	35
Invasive Diagnostic Procedures	27	32
Non-Invasive Diagnostic Procedures	5	13

(See Appendix A for definition of above terms)

TABLE 2
Extraordinary Treatment
 (% of "It depends" responses)

(Health Care Professionals Only)

TREATMENT	%
Cardiopulmonary Resuscitation (CPR)	8
Mechanical Ventilation	10
Intubation	10
Intravenous Therapy	10
Tube Feeding	12
Chemotherapy	12
Radiotherapy	12
Dialysis	10
Ventriculo-Peritoneal Shunts	9
Tissue Plasminogen Activator (TPA)	8
Blood Transfusions	10
Morphine Intravenous Infusion Therapy	7
Total Parenteral Nutrition (TPN)	10
Invasive Diagnostic Procedures	10
Non-Invasive Diagnostic Procedures	19

(See Appendix A for definition of above terms)

TABLE 3
Tube-Feeding - Medical Treatment or Comfort Care Measure
(% of "yes" responses)

(Health Care Professionals Only)

	%
Medical treatment only	38
Comfort care measure only	10
Both, depending on circumstances	49

TABLE 4
Legal Status of Advance Directives
 (% of "yes" responses)

H = Health Care Professionals

E = Emergency Medical Services Personnel

	H	E
Advance directives are legally binding	76	94
HCPs are subject to legal consequences for failure to follow advance directives	69	77
Aware of Manitoba legislation	60	77
Source of knowledge:		
Professional organization/employer	18	79
Media	63	42
Other	16	1
Had input into legislation	1	3
Should have had input	63	65
Favour legislation	82	90
Familiarity with terminology:		
i) Living will	89	97
ii) Advance health care directive	51	65
iii) Durable power of attorney	35	45
Patients should bear the onus for informing HCPs re: advance directives	54	81
Written living wills are legally binding	65	84
Oral living wills are legally binding	15	1
Public statement of treatment choices is legally binding	39	1
Liability Issues:		
Treatment refusal choice is equivalent to assisting suicide if treatment success probable	41	19
Criminal liability for failure to follow such a directive	33	3
Civil liability for failure to follow advance directive	64	52
HCPs have authority to treat in emergencies despite prior expressed wishes	44	19

TABLE 5
Institutional Policy Formulation
(% of "yes" responses)

H = Health Care Professionals

E = Emergency Medical Services Personnel

	H	E
Health care institutions should have formal policies mandating inquiry re: advance directives	90	94

TABLE 6
Bioethical Concepts - Autonomy
 (% of "yes" responses)

H = Health Care Professionals
 E = Emergency Medical Services Personnel
 L = Lawyers

	H	E	L
People want more control re: health care decision-making	97	100	95
Greater control is desirable	93	100	100
Types of Decisions:			
i) aggressive treatment	93	100	95
ii) CPR	91	100	81
iii) non-aggressive, life-prolonging treatment	96	94	90
Most people have sufficient knowledge of medical technology	27	29	33
It is appropriate for the health care team to "take over" when a patient is experiencing a high degree of trauma and stress	76	81	90
Who decides patient's best interests:			
i) patient only	16	32	14
ii) family only	0	0	0
iii) medical team only	5	3	0
iv) patient and family	4	19	4
v) patient and medical team	19	16	14
iv) patient, family and medical team together	52	25	52
Anyone should be able to make a living will	74	61	86
Advance directives only for terminal, irreversible patients	32	34	43
Patient's age should be considered when deciding whether to follow living will	36	16	29
There are occasions when it is appropriate to treat patients against their will	76	81	90

Table 6 Continued on Next Page

TABLE 6 (Continued)
Bioethical Concepts - Autonomy
 (% of "yes" responses)

H = Health Care Professionals
 E = Emergency Medical Services Personnel
 L = Lawyers

	H	E	L
HCPs should have discretion to override advance directives in patient's best interests	43	29	29
HCPs should be able to override living will if they think patient lacked understanding	65	42	57
It is appropriate for the health care team to "take over" decision-making when patient experiencing difficulty due to stress/trauma	79	65	66
HCPs' expertise confers greater authority than patients in decision-making	33	19	33
Reluctant to follow living will if disagree with patient's choices	43	6	33
Patient requests for futile treatment should be followed	35	35	29

TABLE 7
Bioethical Concepts - Decisional Competency
 (% of "yes" responses)

H = Health Care Professionals
 E = Emergency Medical Services Personnel
 L = Lawyers

	H	E	L
In general, the shock and trauma of acute injuries causes decisional incompetency	61	58	33
The pain and trauma of a myocardial infarction causes decisional incompetency	53	32	24
Reluctant to follow advance directive because patient may have changed mind	35	--	43

TABLE 8
Resource Allocation
(% of "yes" responses)

H = Health Care Professionals
E = Emergency Medical Services Personnel
L = Lawyers

	H	E	L
The right to extraordinary medical treatment should be balanced against the availability of scarce medical resources	70	55	81

TABLE 9
Hypothetical Treatment Scenarios
 (% of "yes" responses)

H = Health Care Professionals
 E = Emergency Medical Services Personnel
 L = Lawyers

	H	E	L
a) Vague v. Specific Wording:			
Comfortable with vaguely worded advance directives	51	29	24
Comfortable with treatment-specific advance directives	89	94	--
b) High Technology v. Low Technology:			
Withholding of mechanical ventilation	48	--	66
Withdrawal of mechanical ventilation	65	--	--
Withholding of tube feeding (abstract)	81	--	81
Withholding of tube feeding, IV therapy (Actual patient with acute illness)	38	--	52
c) Withholding v. Withdrawing Treatment:			
Treatment withholding directives should be followed	42	52	52
Treatment withdrawal directives should be followed	89	98	95
d) Acute v. Chronic Illness			
Withholding of tube feeding and IV in patient with chronic illness	85	81	81

Table 9 Continued on Next Page

TABLE 9 (Continued)
Hypothetical Treatment Scenarios
 (% of "yes" responses)

H = Health Care Professionals
 E = Emergency Medical Services Personnel
 L = Lawyers

	H	E	L
e) Irrational Treatment Choices:			
Refusal of CPR in young, healthy person (written directive)	35	68	39
Refusal of CPR in young, healthy person (oral directive)	24	10	29
Refusal of CPR in terminally ill young person (oral directive)	65	19	33
Refusal of thrombolytic drugs for MI	44	23	39
Refusal of blood transfusion	49	35	19
Legally binding?	55	61	--
f) Psychiatric Treatment Issues:			
Refusal of anti-psychotic drugs	23	32	39
Legally binding?	37	42	--
g) Euthanasia			
Comfortable with advance directive	47	35	29
Legally binding?	49	61	--

TABLE 10
Clinical and Personal Experience with Advance Directives
 (% of "yes" responses)

H = Health Care Professionals
 E = Emergency Medical Services Personnel
 L = Lawyers

	H	E	L
Has cared for person with living will or represented client with living will	18	23	5
Comfortable with following it	80	100	--
Has own advance directive	8	3	5
Has considered executing own advance directive	63	70	33

APPENDIX F
COMPARATIVE QUALITATIVE
ANALYSIS

TABLE 1 - TUBE FEEDING AS BOTH A MEDICAL TREATMENT AND COMFORT CARE MEASURE

- 1) Some people might require tube feeding for a short period of time only (e.g. while awaiting surgery) (curative). Others may require it as a comfort measure --- to keep up strength to help deal with pain (e.g., cancer patients) while awaiting death.
- 2) In some cases, such as acute care, it is a medical treatment (e.g., patient on respirator needs to be nutritionally built up to be weaned). In a terminally ill dying patient, I would classify it as a comfort care measure.
- 3) If the patient has a curable or treatable condition that can be dealt with or overcome, nutrition/hydration is medical treatment. If the patient is terminal, it is more likely to be a comfort care measure.
- 4) It depends what stage in the illness -- acute stage (medical treatment) or end stage (comfort care).
- 5) With respect to when it is a comfort care measure -- patients realize they need food to live. If you hold it back, their self-worth is diminished.
- 6) Can be a comfort measure only in rare cases, such as in the case of Mrs. X, a very independent lady with a terminal condition. Because of her gastric outlet obstruction, she could not keep any food down. Mrs. X. just loved to eat and so the doctor decided if this is what she wants then she can eat all she likes, which she did pretty well up to the day she died. She ate and thoroughly enjoyed her pureed diet but it just came back up the nasogastric (NG) tube as fast as it went to her stomach. It was comforting to the family to see her sit up and comment how good it was to taste food again.
- 7) Mostly this is a medical treatment. A nasogastric (NG) tube is most uncomfortable to the patient but the family may feel better if the patient is getting tube feedings.

TABLE 2 - RESPONDENTS' DEFINITIONS OF RELEVANT TERMINOLOGY**A) Heroic Measures**

- 1) Any medical treatment used in a life or death situation.
- 2) Any measures that would sustain or prolong life.
- 3) Aggressive medical intervention for the purpose of prolonging/sustaining life.
- 4) Invasive, aggressive treatment.
- 5) Excessive treatment, "overkill."
- 6) Prolonging life at all costs.
- 7) Aggressive cardio-pulmonary resuscitation (CPR)¹ -- literally doing everything possible to save life.
- 8) Aggressive, life-saving measures such as cardio-pulmonary resuscitation (CPR).
- 9) Cardio-pulmonary resuscitation (CPR).
- 10) Cardio-pulmonary resuscitation (CPR), defibrillation, artificial ventilation.
- 11) The usual "Code 99"² situation -- everything possible to keep the patient alive (intubation, ventilation, drugs, cardio-pulmonary resuscitation (CPR), intravenous lines (IV's)).
- 13) Maximum medical intervention to preserve a patient's life when it is highly unlikely that the patient will survive or if he/she does will have poor quality of life.
- 14) Measures that are invasive, decrease quality of life, and do not usually change outcome.
- 15) Measures with little chance of success.

¹See Appendix A.

²Ibid.

- 16) Those means employed when the chance of survival is minimal.
- 17) Treatments/procedures that are performed even though the chance of success is extremely small.
- 18) Doing absolutely everything possible, even if prognosis is poor.
- 19) Unnecessary measures taken when death is imminent.
- 20) Saving someone's life when it's questionable if the life should be saved.
- 21) Measures taken to prolong life for a terminal patient. (Respondent gave the same definition for extraordinary measures.)
- 22) Cardio-pulmonary resuscitation (CPR) on a 90-year-old with cancer.
- 23) Code 99 call on a terminal patient. Numerous blood transfusions for a terminal patient.
- 24) For example, doing "99" on a cancer patient.
- 25) Risking your own life to save another.
- 26) Anything being done to a person that would not be done if the person dropped in a field 20 miles from nowhere.
- 27) Non-medical act of heroism. (Emphasis included in response.)

B) Extraordinary Measures

- 1) Those means employed which are proven to be of benefit, are invasive in nature and maintain life -- i.e., support life (as opposed to treating a given situation) for extended periods of time, when failure to use these means would result in death.
- 2) Doing whatever possible to sustain (prolong) life.
- 3) Exceptionally intrusive medical treatment.
- 4) Aggressive measures taken -- e.g., intubation, respirator.

- 5) Tube feeds, intravenous lines (IV's), total parenteral nutrition (TPN)³ for prolonged periods; hypodermoclysis⁴ for rehydration vs. administration of analgesia.
- 6) Anything beyond a peripheral intravenous (IV) line and oxygen with spontaneous respirations.
- 7) Same as heroic measures -- i.e. the usual "99" situation -- everything possible to keep the patient alive (intubation, ventilation, drugs, cardio-pulmonary resuscitation (CPR), intravenous lines (IV's)).
- 8) Same as heroic measures, but perhaps not quite as aggressive. (Respondent defined heroic measures as: Maximum medical intervention to preserve a patient's life when it is highly unlikely that the patient will survive or if he/she does will have poor quality of life.)
- 9) Same as heroic measures. (Respondent defined heroic measures as: prolonging life at all costs.)
- 10) Same as heroic measures -- i.e. measures taken to prolong life in a terminal patient.
- 11) Aggressive treatment in the face of overwhelming odds.
- 12) Keeping people on ventilators, etc. with poor prognosis.
- 13) Failing to realize that any further medical treatment is unnecessary.
- 14) Continue to resuscitate even though the patient has no chance of regaining quality of life.
- 15) Measures to prolong life when it is obvious patient has metastatic cancer.
- 16) Treatments/procedures that do not fall within the standard treatment protocols currently in use.
- 17) Treatment not normally used in a given situation.

³Ibid.

⁴Ibid.

- 18) Any medical treatment used as a life-prolonging, treatment that is not necessarily a medically recognized treatment.
- 19) Medical interventions that lie outside of the standard plan for patient management.
- 20) Measures that are not customarily used in patient care.
- 21) Going above and beyond the protocol.
- 22) Surgical interventions such as heart transplants and experimental surgery.
- 23) I'm not familiar with this term.

C) Aggressive Medical Treatment

- 1) All available medical treatment.
- 2) Doing everything possible for a person.
- 3) All possible medical procedures considered in attempt to prolong the patient's life.
- 4) Treating patient with every available medical treatment; sparing nothing.
- 5) All measures and treatments taken to save life.
- 6) Treatment that is out of the ordinary.
- 7) Treatment intervention that involves a high cost:benefit ratio.
- 8) Treatment that is not without risk, and which is intensive and monitored.
- 9) Treatment which hits the medical condition head on. Not necessarily a bad thing, just intensive and thorough but requiring careful monitoring.
- 10) Look for a cause, treat a symptom as it crops up, treat a disease.
- 11) Pursuing viable treatment options.

- 12) I.e., emergency room treatments.
- 13) When treatment consists of expensive treatments and procedures that are not necessary to manage the patient.
- 14) Same as heroic measures. (Respondent defined heroic measures as: the usual "99" situation -- everything possible to keep the patient alive).
- 15) Treatment that is intended to improve a patient's condition but which may prolong a terminal patient's life.
- 16) Resuscitation, artificial ventilation, intravenous lines (IV's), tube feeds, total parenteral nutrition (TPN), hypodermoclysis, invasive procedures,⁵ procedures/tests that will not affect outcome.
- 17) Keeping a patient alive who has no hope of recovery.
- 18) Treatment involving surgical and medical intervention in an attempt to cure a patient when this is clearly futile and causes only grief and false hope for the patient and family members.
- 19) Although the patient has a poor diagnosis, the health team continues to treat with interventions such as Intensive Care Unit (ICU) admission, resuscitation, etc.
- 20) Cardio-pulmonary resuscitation (CPR), lifelines, chemotherapy and radiation in the case of cancer.
- 21) Doing cardio-pulmonary resuscitation (CPR) on a terminal patient.
- 22) Treatment that goes against the wishes of the patient, treatment that prolongs a life where there is no quality.
- 23) Continue with treatment when no quality of life could possibly be present.
- 24) Invasive treatment resulting in decreased quality life for any period of time.

⁵Ibid.

- 25) Having 99 calls, cardio-pulmonary resuscitation (CPR), intubation, intravenous lines (IV's), in the case of the person who wishes to die with dignity.
- 26) The opposite of palliative care.
- 27) CT scans, lab work, etc. on demented 97-year-olds.

D) Comfort Care

- 1) Where all possible medical procedures to prolong life have been exhausted with little results, all that may be left is to attempt to give the patient a sense of self-dignity in the remaining time left.
- 2) To provide the best care nursing-wise to allow the patient to have control (some) over his/her care; to make the patient very comfortable.
- 3) Measures to relieve the patient's pain and keep him/her as comfortable as possible (at home or in hospital) while allowing them to prepare for death with family and friends.
- 4) Total care of physical, emotional, spiritual needs such as positioning in bed, air mattress, urinary catheter if incontinent, pastor to visit and listen to, 24-hr. visiting if desired, IV TKO (intravenous line at a slow drip rate sufficient to keep the vein open); meet food choice wishes if able to eat.
- 5) Anything which provides comfort for a patient, which can include aggressive medical treatment.
- 6) Not aggressive treatment, only trying to keep the patient comfortable.
- 7) Non-life-sustaining measures that provide pain relief or the prevention of painful complications -- e.g., suctioning, turning, range of motion exercises, spoon feeding or other assistance with oral intake (excluding syringe/force feeding), IV's for analgesia, hygiene measures).
- 8) Innocuous, risk-free care such as analgesia, mouth care, skin care.
- 9) Measures that would make a person as comfortable as possible in his or her situation -- e.g., turning, analgesia.

- 10) Any measures, medical or otherwise, that provide comfort for a patient.
- 11) Analgesia as needed, as in terminal cancer; being kept clean, fed and dry; having pleasant company in pleasant surroundings to spend your last days in.
- 12) Pain control.
- 13) Analgesics to keep a patient comfortable.
- 14) Keeping a person comfortable, e.g. decrease pain.
- 15) Treatment given for patient comfort but not to prolong life.
- 16) Doing things to make a patient as comfortable as possible without prolonging life.
- 17) Support physically/mentally by sedation/nursing care.
- 18) Tube feeds, intravenous therapy (IV's), analgesics.
- 19) End stage - do the best you can, relief of pain, nutrition and support.
- 20) Measures performed to keep the patient comfortable, pain free.
- 21) Making sure a patient comfortable during his/her last days.
- 22) Palliative treatment - no real medical treatment but support to keep the patient comfortable.
- 23) Palliative care.
- 24) Measures that are designed to alleviate patient discomfort without addressing the underlying disease process.
- 25) Treatment which alleviates pain and suffering to some extent but does nothing to fight the disease.
- 26) Life support measures/monitors.

E) Best Interests of the Patient

- 1) [This] is an individual definition. It is the continued ability to partake in the life's events that provide meaning, pleasure and fulfilment to the individual -- i.e., quality of life according to the individual's own definition. Decisions to discontinue, not to pursue, or commence treatments should be made based on the patient's continued ability to participate in the aforementioned events (i.e., his "best interests").
- 2) After weighing all of the pros and cons, what would be the most beneficial to the patient. ("Most beneficial" also implies "least suffering.")
- 3) Giving consideration to patient's quality of life with or without treatment.
- 4) Fulfilling patients' wishes either to enable them to recover or to die as pain free as possible and with dignity.
- 5) Those measures taken which would cause the least amount of suffering, the best quality of life, and which are most acceptable to the patient.
- 6) Any options considered to be acceptable to the wishes of the patient should he or she become incompetent.
- 7) Those interests that the patient, the patient's family or advocate and the treatment team have thoroughly reviewed and decided upon.
- 8) Making a decision you think the patient would like to live with.
- 9) Listen to the patient and do what he/she wishes or look at the patient as a 'whole' and do what you think is best.
- 10) The treatment course or goal which provides the patient what he/she wishes with the least amount of discomfort.
- 11) What they want for themselves.
- 12) [That] which provides comfort, quality of life and meets patient desires.
- 13) Any action which benefits the patient's mental and/or physical health and/or quality of life.

- 14) Measures to sustain and improve the patient's quality of life.
- 15) Actively listening to and evaluating the patient's wishes, lifestyle and quality of life.
- 16) That which will restore quality life.
- 17) Maintaining quality of life to the last instance.
- 18) That which promotes the patient's well being (i.e., quality of life).
- 19) To improve a person's life -- quality and length, emotionally, physically and spiritually.
- 20) Treatment which is best for the patient's health.
- 21) Doing what is possible to enable patients to lead healthy and productive lives.
- 22) In the best interests of the patient's "medical health." This includes offering emotional help when the patient or family does not agree with the medical decisions.
- 23) What the family and patient want medically speaking.
- 24) What the doctor feels is necessary -- not necessarily what the patient feels is necessary.
- 25) Medical intervention done with no input from the patient.
- 26) Something done for the patient that he may not want to help him -- intravenous (IV) therapy or analgesic by intramuscular injection (IM), etc.

F) Competent

- 1) 1 > Individual who is alert, oriented and who displays insight (can evaluate both pros and cons) with basic level of knowledge and comprehension when given options); 2 > maintains decision over time; 3 > competence is task specific and must be evaluated on the basis of the decision at hand.

- 2) Being of sound mind and able to receive information, process it, and make a decision regarding the course of treatment.
- 3) The ability to understand and comprehend the effect of one's decisions.
- 4) Able to make an informed decision.
- 5) Sound mind, rational; could be uneducated - or educated. Can be competent but stupid.
- 6) Able to determine/make decisions that are within the knowledge and intelligence of the average person.
- 7) Ability to comprehend and react appropriately to a given situation.
- 8) The ability to arrive at conclusions generally accepted by one's peers.
- 9) Capable and informed.
- 10) When an individual is of the mind and intelligence and age to make a decision.
- 11) Conscious - aware of surroundings.
- 12) Of sound mind and body.
- 13) Someone who is able to complete basic life skills.
- 14) Responding.
- 15) When the person is oriented to place, person, time, family and his medical problems.
- 16) Mentally stable.
- 17) Mentally capable.
- 18) Anyone who can manage their own affairs without harm to themselves or others.
- 19) Oriented to person, time and place, and able to appropriately comprehend and act in their surroundings.

- 20) Able to understand and communicates his understanding of what is being communicated to him.
- 21) Oriented to person, time and place, and demonstrate the ability to understand the cause and effect of their actions.
- 22) Alert, oriented - no psychiatric/alcohol/drug problems.
- 23) Persons aware, knowledgeable.

G) Persistent Vegetative State

- 1) An unconscious, non-responsive state that is maintained for a long period of time.
- 2) A patient who is unaware of his/her surroundings, i.e., comatose, with no hope of regaining consciousness or being able to comprehend or communicate.
- 3) State in which the patient has no ability to comprehend and react to an immediate situation.
- 4) Inability to understand and communicate in any way; plus inability to perform even the simplest tasks required for daily living for a period of at least 30 days.
- 5) A person unable to respond either mentally or physically and who has no hope of improving.
- 6) When the patient has no mental activity and no hope of recovery.
- 7) Unable to respond in any physical or mental way.
- 8) Non-responding for prolonged time period.
- 9) Unresponsive to any stimuli.
- 10) Non-responsive.
- 11) Responds only to painful stimuli.
- 12) Irreversible brain damage.
- 13) No brain function.

- 14) Brain waves on electroencephalogram (EEG) - brain dead, never regain consciousness again.
- 15) When there are no signs of brain activity -- e.g. no response to any stimulus. Brain scan, etc. shows that person is "brain dead."
- 16) When an individual does not respond to treatment successfully -- e.g., "brain dead."
- 17) No brain waves, no motor skills.
- 18) No brain waves, unlikely to develop brain waves in future.
- 19) No normal brain responses/activity.
- 20) A state of brain activity beyond hope of recovery.
- 21) Patient unable to sustain his/her own life (respiratory and cardiac function) without mechanical intervention.
- 22) No quality of life.
- 23) State requiring care for all physical needs.
- 24) Unable to function on their own outside hospital.

TABLE 3 - RESPONDENTS' PROPOSED ADVANCE DIRECTIVES

- 1) Unable to comment on specific clauses but I would focus on need to clearly convey which procedures and at what point I would request that treatment be withdrawn.
- 2) No treatment if rendered quadriplegic and comatose.
- 3) No life support measures when vegetative state is reached.
- 4) Comfort measures only if comatose or terminally ill.
- 5) If comatose for extended period of time and physician feels that not likely to regain consciousness to level of normal functioning, do not maintain mechanical life support.
- 6) No long term life support procedures, treatment only until such time as the prognosis was grim and there became no hope for unassisted life support or quality of future existence would be less than prior to treatment.
- 7) In the event of accidental or irreversible illness or injury, I do not want to be kept alive by artificial means.
- 8) If I were in an accident and could not live without life support, I would not wish to be placed on it for longer than one week.
- 9) If I had a terminal disease, I'd rather just go peacefully than being in more pain than necessary. Not to have any treatment if it would mean I would be a "vegetable" and not be able to recognize my family.
- 10) If I had terminal cancer, I don't want surgery that will not benefit me. This is equivalent to mutilation. I would want pain medication and palliative care.
- 11) If I were to have an irreversible condition, I would refuse all treatment other than comfort measures -- analgesic, turning, suctioning, etc. As age advances, I would add clauses to the effect of artificial prolongation of life versus quality of life -- dignity, independence, presence of friends/family, etc. I may decline cardio-pulmonary resuscitation (CPR), intravenous (IV) therapy, surgery, clinical investigations, total parenteral nutrition (TPN), tube feeds, chemotherapy.

- 12) If comatose or vegetative state, I do not want to be kept alive by mechanical means.
- 13) I don't feel comfortable with IV's that would keep me alive if I choose not to eat.
- 14) I do not want to be kept alive by artificial hydration and nutrition. I've cared for many, many people being tube fed for years, being kept alive by tube feeds, and I find this disgusting and inhumane.
- 15) No resuscitation efforts in case of severe central nervous system damage (e.g., severe head trauma) including no cardio-pulmonary resuscitation (CPR), intubation or prolonged mechanical ventilation beyond the initial assessment period (24-48 hours).
- 16) If I had ALS,⁶ I would not want a permanent ventilator.
- 17) If no longer competent or have Alzheimer's disease,⁷ no resuscitation; if in an accident and comatose, no ventilator; if unable to care for myself or I have terminal cancer, no resuscitation and lots of pain medication.
- 18) If I have Alzheimer's disease or severe mental problems, no resuscitation, comfort measures only.
- 19) Provisions for no resuscitation or aggressive treatment such as ventilation, tube feeding, intravenous (IV) antibiotics. If in an accident and had irreparable brain damage or developed Alzheimer's or was in a vegetative state due to an accident or illness. Also no resuscitation if over 65.
- 20) If I had cancer, multiple sclerosis or ALS, treat me with comfort measures only and allow me to die with dignity. I define comfort measures as: analgesics, antibiotics, hygiene and turning, psychosocial care (it is important for care givers to talk to and interact with patients).
- 21) If I have a stroke and there's no hope of recovery and I'm not able to function with some degree of independence, don't keep me alive indefinitely by tube feedings.

⁶See Appendix A.

⁷Ibid.

- 22) To be healthy and independent; if not, leave me be.
- 23) No resuscitation, no life support - if unable to function in a manner that would constitute some "quality of life," then don't bother.
- 24) I'm a very independent person. I could not handle being totally dependent with respect to bodily functions, couldn't handle being quadriplegic, would rather not live than live like that (i.e., totally dependent on others for most basic physical needs.
- 25) I want no extraordinary measures (now existing or future inventions) to be used if I was suffering from any progressive, incurable or chronic illness or if I was incapacitated by a traumatic event such as a motor vehicle accident, cerebrovascular accident or myocardial infarction, which left me incapable of functioning physically, mentally or emotionally. I would consider extraordinary measures [to be] anything that prolonged life in an undignified and unnecessary way and didn't add to my health and comfort. I may specify particular treatments but also name one or two trusted friends or family members to make decisions on my behalf.
- 26) If unable to function physically and/or mentally, I would want to be gone. I don't want to be trapped in my body. I would like to be euthanatized in that situation -- it's so humane.
- 27) Send me Dr. Kevorkian. I would rather be dead than suffer the way I have seen many patients suffer. It's not humane."
- 28) If I'm in severe pain with a terminal illness, let me go. I would want a visit from Dr. Kevorkian.
- 29)
 1. The living will should only be used if I am unable to act on my own behalf, e.g., comatose, significant or severe brain damage.
 2. I would only want it to deal with situations that are:
 - a) terminal in nature and there is extreme pain and suffering;
 - b) irreversible and likely to leave me comatose or severely brain damaged for the rest of my life.

3. I would not want it to be used for situations where despite pain and suffering or a comatose state, there was a good possibility of 100% recovery.
4. I would want to review the living will on a regular basis (every 5 years) and update it if necessary for one of several reasons:
 - a) advances in medical technology
 - b) changes to my health status - e.g., perhaps, I am now a para- or quadriplegic. I may wish to alter conditions of the will
 - c) I may wish to add/change names of individuals who are instructed to act on my behalf.
- 30) All and every technique available to sustain reasonable quality of life, including availability of scarce medical supplies.
- 31) Refusal of intubation and mechanical ventilation no matter what the medical indications, duration of therapy, and expected outcome. I have a profound fear of being intubated.

APPENDIX G
EXAMPLE OF PRE-HOSPITAL
ADVANCE DIRECTIVE

I, _____, request limited emergency medical care as herein described.
(name)

I understand DNR means that if my heart stops beating or if I stop breathing, no medical procedure to restart breathing or heart function will be instituted.

I understand this decision will not prevent me from obtaining other emergency medical care by pre-hospital care providers and/or medical care directed by a physician prior to my death.

I understand I may revoke this directive at any time.

I give permission for this information to be given to the pre-hospital care providers, doctors, nurses, or other health personnel as necessary to implement this directive.

I hereby agree to the "Do Not Resuscitate" (DNR) order.

Patient/Guardian Signature _____ Date _____

Witness _____ Date _____

REVOCATION PROVISION

I hereby revoke the above declaration.

Signature _____ Date _____

I AFFIRM THIS DIRECTIVE IS THE EXPRESSED WISH OF THE PATIENT/PATIENT'S GUARDIAN, IS MEDICALLY APPROPRIATE, AND IS DOCUMENTED IN THE PATIENT'S PERMANENT MEDICAL RECORD.

In the event of an acute cardiac or respiratory arrest, no cardiopulmonary resuscitation will be initiated.

Physician's Signature _____ Date _____

Address _____ Facility or Agency Name _____

THIS FORM WILL NOT BE ACCEPTED IF IT HAS BEEN AMENDED OR ALTERED IN ANY WAY.

Prehospital DNR request form:
an advance directive to limit the
scope of emergency medical care
(Sosna et al.)

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