The legal validity of an advance refusal of medical treatment in South African law (Part 2)

Louise Jordaan
BProc LLB LLD
Professor, Department of Criminal Law, University of South Africa

OPSOMMING

Die regsgeldigheid van 'n gebeurlikheidsweiering van mediese behandeling in die Suid-Afrikaanse reg (Deel 2)

Mediese gebeurlikheidsaanwysings stel persone in staat om mediese behandeling in die toekoms, wanneer hulle nie meer in staat is om wilsbesluite te neem nie, te weier. 'n Mediese gebeurlikheidsaanwysing is 'n lewende testament waarin die outeur weier om mediese behandeling in bepaalde omstandighede in die toekoms te ondergaan. Dit kan ook bestaan uit 'n volmag waarin die outeur 'n ander persoon aanstel om namens hom of haar in die toekoms mediese behandeling te weier. In Suid-Afrika is die regsgeldigheid en afdwingbaarheid van sodanige gebeurlikheidsaanwysing onseker. In die eerste gedeelte van hierdie bydrae wat in 2011 *De Jure* 32 verskyn het, is die regsposisie soos dit tans in Suid-Afrika daar uitsien, bespreek. Die etiese norme wat in die mediese beroep geld is oorweeg en met die huidige regsposisie vergelyk. Voorts is die relevante grondwetlike waardes wat in ons samelewing geld, kontekstueel ontleed en teen bepaalde belange van die gemeenskap opgeweeg. Hierdie ontleding en belange-afweging het tot die gevolgtrekking gelei dat mediese gebeurlikheids-aanwysings in beginsel as regtens afdwingbare wilsbesluite erken behoort te word.

In die tweede gedeelte van hierdie bydrae word aandag geskenk aan die etiese oorwegings wat 'n rol behoort te speel by beantwoording van die vraag of 'n mediese gebeurlikheidsaanwysing in bepaalde omstandighede as regtens afdwingbaar beskou behoort te word. Die ontwikkelinge in buitelandse regstelsels word dan oorweeg en empiriese navorsing wat aldaar onderneem is om die doeltreffendheid van gebeurlikheidsaanwysings in die praktyk te evalueer, word krities ontleed. Die slotsom wat bereik word, is dat die Suid-Afrikaanse parlement oorweging moet skenk aan die destydse voorstelle van die Suid-Afrikaanse Regskommissie in hierdie verband en dat statutêre erkenning aan die regsgeldigheid van mediese gebeurlikheidsaan-wysings verleen moet word. Die ondervinding in buitelandse regstelsels dui egter daarop dat blote statutêre erkenning van die regsgeldigheid van gebeurlikheidsaanwysings nie enige noemenswaardige verandering in die praktyk teweeg bring nie. 'n Verandering in opvattings word slegs teweeggebring deur behoorlike opvoeding en die instelling van opleidingsprogramme en ondersteuningstelsels in gesondheid-sorginstellings soos klinieke en hospitale. Daar dus word aan die hand gedoen dat 'n holistiese benadering gevolg moet word, wat beteken dat die staat self betrokke moet raak by die implementering van doeltreffende strategieë om sodoende groter bewuswording van die reg op selfbeskikking van pasiënte by gesondheidsorg-werkers sowel as die breë publiek te bewerkstellig.

6 The Exercise of Prospective Autonomy in Advance Directives – Some Ethical Concerns

In practice, the enforcement of advance non-treatment directives can be extremely problematic. The concern is that the future cannot be anticipated with certainty. It is difficult enough for a physician to fully inform a patient with decision-making capacity of all the possible consequences of a medical intervention or medical treatment. But while the principle of "informed consent" is perfectly valid in the context of a contemporaneous decision, it may be argued that it cannot apply in *all* cases of prospective non-treatment decisions. The majority opinion in the literature is that an advance directive has the equivalent legal force of a contemporaneous refusal of treatment. But there are those who question the legal validity of advance refusals of medical treatment on ethical grounds.[69] The main concern is that advance directives lack continuous communication between doctor and patient; they lack contemporary information and input from the patient at the critical moment. For a patient to issue an instruction on non-treatment of a hypothetical condition that might arise during some future time of decisional incapacity is questioned, especially if the patient has never suffered from the particular disability or has never anticipated a particular disability. Dresser[70] points out that decisions to hasten death expressed in advance directives are most problematic in cases where people are not permanently unconscious but conscious, incompetent and suffering from progressive and incurable dementia. People often complete advance directives with little understanding of the meaning or implications of their decisions.[71] Before implementing directives to hasten death, it should be required of people to exhibit a reasonable understanding of the choices they are making. Dresser is concerned that people might be mistaken about their future *experiential* interests as incompetent individuals. She argues that to require, as a matter of policy, absolute adherence to advance directives would mean that people who, for instance, suffer from dementia, are denied the freedom other competent people enjoy to change their previous decisions that conflict with their subsequent experiential interests.[72] She argues that interference with choices that originate in insufficient or mistaken information amounts to justified paternalism. Her concern relates also to

69 Rich "Advance directives: The Next Generation" 1998 *Journal of Legal Medicine* 63 67 observes: "When … a healthy person states preferences for treatment or non-treatment of a hypothetical condition that might arise during some possible future period of decisional incapacity, the level of potential uncertainty is greatly increased. The question then arises whether the uncertainty is so great that, as a matter of ethics, law and public policy, it is reasonable to honour such declarations." Buchanan & Brock "Deciding for Others" in Battin, Francis & Landesman (eds) *Death, Dying and the Ending of Life* (2007) 205 248-249 question the ability of a competent person to predict a future situation and express concern about proper procedural safeguards for future decision-making.

70 Dresser "Dworkin on dementia: 'Elegant Theory, Questionable Policy'" in *Bioethics – An Anthology* (eds Kuhse & Singer)(1999) 312 ff.

71 Dresser 315.

72 *Ibid*.

the definition of "person" as considered by Parfit.[73] He claims that in one lifespan, a body may house more than one morally relevant entity. The defining characteristic of a so-called "person" is psychological continuity or connection between past, present and future cognitions. By becoming incompetent as a result of a loss of cognitive abilities, for example, in the case of dementia, the person's continuous self is disrupted. He or she becomes another morally relevant person. Arguably, an advance directive has no moral validity in such cases because it is a decision made by person A in respect of person B.

But Dworkin[74] expresses the view that core values such as autonomy and dignity are "critical interests" of a person which, in the context of dying, should have precedence over the mere "experiential interests" of a person. Therefore, the critical interests of the competent "person A" expressed in an advance directive are valid en enforceable in respect of the incompetent "person B" as well, even if person B still has experiential interests, for example, enjoying food and the company of friends. Dworkin also relies on the principle of beneficence to substantiate his point of view. He argues that it is also in the best interest of a patient to honour his or her choices expressed at a stage when he or she was still competent. In his view, a disregard of a person's critical interests (or core values) as previously expressed, would not only amount to unjustified paternalism but would lack mercy as well.[75] Bernat[76] questions Dworkin's argument on the ground that "it cannot be morally defensible to let a person die whose life seems to be happy and whose former critical interests are no longer of relevance because they are not part of his current personality". MacLean[77] takes a more compromising position by, *inter alia*, drawing an analogy with the parent-child relationship. He argues that recognition of decisional authority residing in the former competent self is justified because the former self can be viewed as the protector of the later incompetent self. He adds the *caveat*, however, that similar to the parent-child relationship the decisional authority should not be absolute but subject to the same limits as parental authority. In his view, the advance directive should be respected "unless it is demonstrably contrary to the present-self's best interests, with the burden of proof falling on the intervening party".[78]

---

73 Parfit *Reasons and Persons* (1984) 204-206.

74 Dworkin *Life's Dominium – An Argument about Abortion and Euthanasia* (1993) 190-213. Dworkin explains (201-202) that critical interests are "[c]onvictions about what makes life good as a whole … [t]hey represent critical judgments rather than just experiential preferences". He argues (199) that "how we think and talk about dying – the emphasis we put on dying with 'dignity' – shows how important it is that life ends *appropriately*, that death keeps faith with the way we wanted to have lived".

75 Dworkin 231.

76 Bernat "The Living Will: Does an Advance Refusal of Treatment made with Capacity Always Survive any Supervening Incapacity"? 1999 *Medical Law International* 5-15.

77 MacLean "Advance directives, future selves and decision-making" 2006 *Medical LR* 291 315-320.

78 MacLean 2006 *Medical LR* 320.

A related concern is the enforcement of widely-formulated advance directives in accordance with the wishes of the patient. Living wills are often drafted in vague terms because people wish to cover a variety of possible circumstances. It is therefore not always easy to determine the patient's wishes with any certainty. The enforcement of an advance directive expressed in broad terms in other circumstances than those where the patient is terminally ill and further medical treatment is futile, is extremely problematic. Instructions in living will templates are couched in terms such as "I do not want my life to be prolonged if my condition is hopeless". Sometimes a relative or friend refers to an oral communication made by a previously competent person expressing the wish that "I don't want to be like that" or "please let me die once I become soft in the head". In such circumstances, it is very difficult for a physician to determine what particular circumstances justify the termination of life-supporting medical treatment. But consider the following example, which, on its face, is not vague. X makes a living will which provides that medical treatment should be withheld if, as a result of an accident or illness, he has complete or almost complete loss of ability to think or communicate with others. X is involved in an accident, is paralysed and has brain damage which renders him incompetent to communicate. However, he is not in a coma and cannot be diagnosed as being terminally ill. The question arises whether X should receive antibiotics if he gets pneumonia. Without any other evidence of the wishes of the patient, physicians would most probably resort to a clinical judgment of "the best interests of the patient", which would, in most such cases, result in the continuation of life-prolonging medical treatment.

Such problems may be overcome by educating patients to issue detailed and comprehensive advance directives which set out all the possible circumstances in which medical treatment should not be given and also the particular medication or treatment which should not be administered. Ideally, the patient should be advised by his or her physician in the context of an on-going physician-patient relationship.[79] The physician can explain the important medical implications to the patient with due regard to the patient's values and medical history. In South Africa, however, this would disenfranchise millions of patients who do not have a real ongoing relationship with a personal physician. It is therefore important that not only physicians in private practice, but also state health-care institutions such as hospitals and nursing homes

79 See the views of Kusman "Swing low, Sweet Chariot: Abandoning the Disinterested Witness Requirement for Advance Directives" 2006 *American Journal of Law and Medicine* 112: "Without the input of a doctor, however, the substance of the directive may be fatally defective. Many living wills contain ambiguous or contradictory instructions, reflecting a lack of comprehension of the medical issues and treatment possibilities involved." See also Hickey "The Disutility of Advance Directives: We know the Problems, but are there Solutions?" 2003 *American Health Law Association Journal of Health Law* 455 ff for a discussion of physician-imposed and patient-imposed barriers to completion of advance directives in the USA.

provide information to patients about their right to make advance directives. Support systems should be created as well to assist patients who wish to make advance directives.

Of course, uncertainty in advance medical directives can never be eliminated completely. It would seem that a combination of an instructional directive (such as a living will) and a proxy directive (in a single document or in alternative documents) would be the most effective way to ensure that a patient's wishes are honoured.[80] The proxy (for example, a person trusted by the patient) could ensure that the living will is honoured by physicians, and if the provisions of the living will are vague, the proxy could give the necessary guidance to physicians to determine the wishes of the patient. The use of combined directives would also overcome the problem of advances in medical science which the patient could not have foreseen at the time of making the advance directive.

Whatever policy is adopted, it is clear that the enforcement of advance directives cannot be achieved solely through broadly formulated ethical guidelines for health-care practitioners. This is precisely why a movement has developed in other legal systems in support of comprehensive legislative regulation of all issues concerning advance directives. The legislative measures that have been introduced elsewhere may be of value for future law reform in South Africa. But it is also important to investigate whether legal recognition of advance non-treatment directives has resulted in effective enforcement of such instructions in other jurisdictions. The discussion that follows focuses essentially on the most significant developments in other legal systems. Relevant empirical data collected in some of these legal systems are also evaluated.

7 The Recognition and Enforcement of Advance Directives in Other Legal Systems

In response to two highly publicised cases, those of *Karen Quinlan*[81] in 1976 and *Nancy Cruzan*[82] in 1991, the United States of America took the lead in regulating the enforcement of advance directives through the enactment of various legislative measures. Both these cases involved requests to discontinue life-support mechanisms by the parents of young women who were in a permanent vegetative state. Quinlan was a woman in her early twenties who was in a persistent vegetative state with no hope of recovery. Her father's request to have her respirator disconnected was granted by the New Jersey Supreme Court on the ground that she had a right of privacy to choose to forego a vegetative

80 Cf the views of Dunlap "Mental Health Advance Directives: Having one's Say" 2000 *Kentucky LJ* 327 348.
81 *In re Quinlan* 355 A2d 647 (NJ) 429 US 922 (1976).
82 *Cruzan v Director Missouri Dept of Health* 497 US 261 (1990).

existence and die of natural causes. Quinlan had no living will but had previously expressed her desire to avoid life-prolonging medical treatment in casual conversation. The first *Natural Death Act* which sets out requirements for advance directives was passed in California in 1976, following the *Quinlan* case.

In *Cruzan* the Supreme Court had to decide whether an incompetent person has the right to require the removal of life-sustaining treatment. Nancy Cruzan was in a persistent vegetative state and her parents requested the hospital to remove the treatment on the ground that such steps would be in accordance with her wishes expressed orally when she was still competent. The hospital refused and the parents applied for a court order. The Missouri court refused to grant such an order, ruling that it had not been proved by "clear and convincing evidence" that this was her wish.[83] The Supreme Court granted *certiorari* and validated the "clear and convincing" evidence standard of the state of Missouri. It held that a person has a constitutional liberty interest in refusing unwanted medical treatment and that for the purpose of the case the court would assume that a competent person has the right to refuse life-saving hydration and nutrition.[84] However, the court balanced Cruzan's liberty interest against various state interests, including the interest in the protection and preservation of human life.[85] It found that the high burden of proof required in Missouri served the state's interest without infringing too much on the individual's liberty interest and that the requirement was therefore constitutional.

Although the rulings in both cases ultimately supported the right to refuse life-sustaining interventions, the importance of clearly documenting a patient's preferences in advance was reaffirmed.[86] Currently, each one of the fifty states has adopted legislation which recognises the legal validity of advance directives in respect of refusal or withdrawal of life-sustaining medical treatment in defined circumstances. These include living wills, durable powers of attorney which allow for the appointment of surrogate decision-makers and do-not-resuscitate orders. Policy makers in Australia and Canada have followed suit and introduced similar legislation.[87] Although the various legislative models are of interest, it is impossible to discuss all of them in detail. The

83 265-269.
84 278-279.
85 280.
86 After the decision in *Cruzan* most states introduced legislation to codify their evidentiary requirements with respect to the treatment preferences of incompetent patients. These so-called "Living Will Statutes" or "Natural Death Acts" set out the requirements for advance directives but they vary widely from state to state. See Kusman 2006 *American Journal of Law and Medicine* 96.
87 The first "living will" legislation was introduced in South Australia (the *Natural Death Act* 1983(SA)) and similar legislation followed in 1988 in the Northern Territory (the *Natural Death Act 1988* (NT)). At present five of the eight states and territories have advance-directive legislation whereas only

continued on next page

discussion focuses on the most important developments to the extent these may be of value for reform of South African law.

The current legal position in the United States of America is summarised briefly. State legislation on advance directives varies both in form and in substantive requirements. In certain states, even artificial nutrition and hydration are viewed as basic care and may not be refused by the patient.[88] This issue remains highly controversial and has been the topic of endless debate. The current trend is to do away with too many formal requirements for living wills.[89] Some state legislation also provides for sanctions to be imposed if healthcare practitioners fail to honour advance directives. These include the imposition of penalties for noncompliance through state licensing procedures.[90] But there seems to be general consensus that the criminal sanction is not an appropriate remedy for noncompliance.[91] Specific provisions are also included in legislation in terms of which physicians who have honoured advance directives in good faith are indemnified.[92]

---

four states have legislation allowing the appointment of a proxy for health care decision-making. In Canada each province has advance-directive legislation. See Brown "The law and Practice associated with Advance Directives in Canada and Australia: Similarities, Differences and debates" 2003 *Journal of Law and Medicine* 59 59-60.

88 For instance, the Missouri statute excludes specifically from the phrase "death prolonging procedure" artificial nutrition and hydration or the administration of any medication. In the state of Colorado, the living will statute requires declarants to state specifically that they do not wish to receive artificial nutrition and hydration when they lack mental capacity in future. See Rich 1998 *Journal of Legal Medicine* 75.

89 Kusmin 2006 *American Journal of Law and Medicine* 113-116.

90 See Webster "Enforcement Problems arising from Conflicting Views of Living Wills in the Legal, Medical and Patient Communities" 2001 *University of Pittsburg LR* 793 799-801 for the position in the United States of America. In the United Kingdom, is has been reported that the General Medical Council is to announce that doctors who fail to respect the advance directives of terminally ill patients refusing treatment once they become incompetent may be struck off the roll. See http://www.telegraph.co.uk/health/healthnews accessed on 2010-05-20.

91 Webster 2001 *University of Pittsburg LR* 799-801. In a minority of jurisdictions in the United States of America minor criminal penalties may be imposed for an intentional and bad-faith failure to comply with a living will. Perry "Legal Implications for Failure to comply with Advance Directives: An Examination of the Incompetent Individual's Right to Refuse Life-Sustaining Medical Treatment" 2002 *Behavioural Sciences and the Law* 253 266-268 discusses in more detail the relevant civil causes of action which may be instituted for a refusal to honour an advance non-treatment directive. These include an action in the tort of battery; an action for pain, suffering and mental anguish for the patient and the family if life-sustaining treatments are administered contrary to the wishes of the patient or his or her surrogate. He points out that an action based on wrongful life or wrongful prolongation of life has also surfaced in American courts but that such claims have not been successful.

92 Webster 2001 *University of Pittsburg LR* 799. See also Wilmot, White &

continued on next page

In Europe, section 8(1) of the European Convention for the Protection of Human Rights (ECHR) set the tone for legal reform in this particular area of law. This section protects the individual's right to privacy.[93] In *Pretty v United Kingdom*[94] the court recognised that "the imposition of medical treatment, without the consent of a mentally competent adult patient, would interfere with a person's physical integrity in a manner capable of engaging the rights protected under article 8(1) of the Convention".[95]

Although the legal validity of an advance refusal of medical treatment has not as yet been tested by the court, a challenge in terms of section 8 (of a refusal to honour such a directive) is clearly well-founded. In Europe, the most recent developments took place in England and Wales, as well as Germany. Although advance directives were recognised previously as valid and enforceable at common law in England and Wales, *The Mental Capacity Act 2005* came into force in 2007 and now clarifies the common-law rules.[96] An advance refusal of medical treatment may be made by a person eighteen years or older in writing or orally, but an advance refusal of life-sustaining treatment should be in writing, witnessed and signed.[97] The refusal can extend to artificial nutrition and hydration but not to "basic or essential care" such as warmth, shelter, hygiene and the offer of food and water by mouth.[98] To be valid, an advance refusal should be applicable to the situation which means that there should be no reasonable grounds for believing that circumstances

---

Howard "Refusing Advance Refusals: Advance Directives and Life-Sustaining Medical Treatment" 2006 *Melbourne University LR* 211 220-236 for a detailed discussion of the circumstances in which a health professional or a court is permitted to disregard an advance directive in Australian law. These circumstances include: where there has been a change in circumstances for example if the patient is pregnant; if there is evidence of an intention to revoke the advance directive; where there is uncertainty as to the meaning of a directive eg, where the language is vague and imprecise or if it is based on incorrect information or an incorrect assumption.

93 The relevant part of s 8 of the European Convention of Human Rights provides: 1. "Everyone has the right to respect for his private and family life …" 2. "There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others."

94 35 EHRR 1.

95 Par 63.

96 *Mental Capacity Act 2005*. See Jones & Jones "Advance Directives and Implications for Emergency Departments" 2007 *British Journal of Nursing* 220 and Bell "The Legal Framework for End of Life Care: A United Kingdom Perspective" 2007 *Intensive Care Medicine* 158 for a discussion of the provisions of the act and its possible application in practice.

97 Ss 24(1); 25(5) and 25(6) of the *Mental Capacity Act 2005* at www.legislation.gov.uk/ukpga/2005/9 (accessed 2011-02-02).

98 S 9.28 of the *Mental Capacity Act Code of Practice 2007* at www.publicguardian.gov.uk/docs/mca-code-practice-0509 (accessed 2011-02-02).

exist which the person did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.[99]

There is no prescribed statutory form required for the validity of an advance directive or a requirement that an advance directive be reviewed over time. It is significant that the circumstances are not confined to "terminal" illness. The act also provides for the appointment of a health care proxy by means of a lasting power of attorney through which persons may appoint someone else to make health care decisions on their behalf, should they lose the capacity to decide for themselves.[100] The British government has been pro-active and created an institution in 2007, the "Office of Public Guardian", to support and promote decision making for those who would like to plan for their future within the framework of the *Mental Capacity Act 2005*.[101]

In Germany, the right of an individual to refuse medical treatment in an advance directive has been recognised by the courts as an expression of the right to self-determination derived from various provision of the *Grundgesetz*.[102] Because there has been uncertainty about the validity of such directives in various circumstances, legislation was adopted in 2009 which considerably clarified the position.[103] For a living will to be valid, the requirements are the following:[104] If a competent adult person had given written instructions that medical treatment should not be administered if he or she became incompetent, it must be determined whether the circumstances in which future treatment should be refused correspond to the current treatment situation. If this is the case, effect should be given to the will of the patient. Such a living will may be revoked without any formal requirements. If there is no living will, or if the instructions in the living will do not correspond to the treatment situation, the wishes of the patient or the presumed wishes of the patient should be determined on the following basis: Whether the patient has consented to or refused medical treatment or whether the patient would have consented to or would have refused medical treatment. The presumed wishes of the patient must be determined in terms of concrete indications. What should be considered in particular are earlier oral or written statements by the patient, ethical or religious convictions and personal value systems of the patient. Neither the type of condition or disease from which the patient is suffering or the stage thereof is of any relevance. (In other words, it is not limited to cases of terminal illness). It

99 S 25(4)(c) of the *Mental Capacity Act 2005*.

100 Ss 9-14.

101 See www.publicguardian.gov.uk (accessed 2011-02-02)

102 In a civil case decided in 2003, The *Bundesgerichthof* described an advance directive as an expression of the patient's continuous right to self-determination in terms of the *Grundgesetz*. See 2003 *Neue Juristische Wochenschrift* 1588 1591.

103 Ss 109a and 109b *Bürgerliches Gesetzbuch* (BGB) as amended on 2009-09-01 (BGB1 2009 2286). See Clemens (ed) *Handbuch des Arztrechts* 6 ed (2010) 1512-1516 for a discussion of these provisions.

104 Ss 1901a and 109b *BGB* discussed in Clemens *et al* 1512-1516.

is also stated explicitly that no person may be compelled to make an advance directive.[105]

In the rest of Europe the position varies considerably, depending on socio-cultural and philosophical traditions.[106] In countries where specific laws assign binding force to advance directives, the minimum requirements that must be fulfilled include a valid form (for example, a written and signed document, and in some countries the presence of witnesses to the signature); correspondence between the circumstances envisaged and those that exist; time validity and the absence of revocation of the document.[107] In Spain a compromise between values of autonomy on the one hand and beneficence on the other hand requires more substantial limitations such as conformity with good clinical practice.[108] In Italy, there are no clear laws on advance refusal of medical treatment and similar to the position in South Africa, there is no clarity about the circumstances in which advance directives are viewed as legally enforceable instruments.[109]

Jurisdictions in which advance directives have strong legal status are Germany, Switzerland, Austria, the Netherlands and Belgium.[110] The legislation introduced in the Netherlands is discussed in more detail, because it has been in effect for more than fifteen years and several empirical research projects have been undertaken more recently to determine its effectiveness. Considered from a legal point of view, the status of a written refusal of future treatment in the Netherlands is described as "one of the strongest in the world".[111] The relevant law, the *Wet op de Geneeskundige Behandelingsovereenkomst*, provides that if a person of sixteen years or older is not competent, a doctor is required to honour a refusal of treatment made in writing when the patient was still competent.[112] There are neither limits on the treatments that can be refused nor on the circumstances in which a written refusal is effective. There are also almost no formal requirements (such as witnesses; regular renewal or not even a signature or a date is required). Even the

105 *Ibid.*

106 See Andorno, Biller-Andorno & Brauer "Advance Health Care Directives: Towards a Coordinated European Policy?" 2009 *European Journal of Health Law* 207 212-223.

107 See Andorno *et al* 2009 *European Journal of Health Law* 213-218 for a discussion of the Spanish law.

108 Andorno *et al* 2009 *European Journal of Health Law* 215.

109 See Servillo & Striano "End of life: Still an Italian Dilemma" 2008 *Intensive Care Medicine* 1333 1335. These writers encourage the implementation of effective strategies to address the problems encountered in Italy with the enforcement of advance directives.

110 In France advance directives only have advisory force and are not binding upon physicians. See Griffiths, Weyers & Adams *Euthanasia and Law in Europe* (2008) 383-385.

111 Griffiths *et al* 58.

112 S 450 (3) *Wet op de Geneeskundige Behandelingsovereenkomst* (Wet 1994-11-17 Stb. 1994 837, tot wijziging van het Burgerlijk Wetboek) at www.rbng.nl/userfiles/file/wettenWGB0 accessed on 2011-02-10.

requirement that it should be in writing is questioned on the grounds that an oral refusal in advance by a competent patient excludes the presumption of consent.[113] There must be no doubt as to the authenticity of the document; the identity and competence of the author and the voluntariness of its execution.

But there seems to be room for the application of the principle of beneficence or considerations of what physicians regard as being in the best interest of the patient. A doctor can depart from the written instruction if he considers that there are well-founded reasons (*gegronde redenen*) for not doing so.[114] Dutch writers point out that there is general agreement that the doctor's personal views concerning the instruction cannot amount to a well-founded reason.[115] They are of the opinion that "well-founded reasons" refer to doubt about the authenticity of the document; the competence of its author and the meaning of the instructions.

However, empirical studies conducted in the Netherlands indicate that the *de facto* position is considerably different from what was anticipated with the enactment of this legislation.[116] One of these studies indicate that in 2005 (ten years after the legislation came into effect) advance directives had an influence in less than 2% of deaths that occurred in intensive care units (ICUs) and that fewer than 10% of doctors in ICUs considered a written advance directive as binding.[117] A more recent study has revealed that advance directives are made by less than 1% of the population as a whole, but that it is somewhat higher for patients in nursing homes (5%) and even higher for patients of general practitioners who died in the year preceding the study(almost one in ten).[118] Research indicates that a quarter of the nursing-home doctors and almost half of the general practitioners responded that they would not follow an advance directive which differed somewhat from their medical judgment. If a directive would be directly opposed to their judgment, the rate rises to almost 60% for nursing home doctors and 90% for general practitioners.[119] So it would seem as if legislative recognition of the binding nature of advance directives in itself has not encouraged doctors to honour such instructions. Some Dutch writers express the point of view that the Dutch legislation cannot be blamed for the position in practice. In their view, the blame lies with the Dutch government that

113 See the views of Griffiths *et al* 58 n 27.
114 S 450(3) *Wet op de Geneeskundige Behandelingsovereenkomst*.
115 See Griffiths *et al* 59.
116 Griffiths *et al* 163, relying on a survey conducted by Kleijer "Het wordt geregeld …" *Een onderzoek naar (zelf)-regulering bij het staken van de behandeling op Intensive Cares* (Dissertation 2005 University of Groningen); Vezzoni *Advance Treatment Directives and Autonomy for Incompetent Patients in Law and Practice* (2008) 201-209.
117 See Griffiths *et al* 162-163 n 45, relying on the research conducted by Kleijer.
118 See Griffiths *et al* 163 relying on the research conducted by Vezzoni.
119 *Ibid*.

"has done nothing to promote the use of treatment directives, to increase their quality, or to increase the willingness of doctors to abide by the instructions they contain".[120] Professional bodies, hospitals and nursing homes have also not taken steps to promote their use by patients. Similar to the position in South Africa, persons interested in drafting advance directives must approach the Euthanasia Association since healthcare workers are reluctant also in the Netherlands to become involved in assisting people who wish to make advance directives.

In Germany, an empirical survey undertaken in 2005/6 has shown that the number of people in possession of an advance directive varied between 3.5% (according to a survey on the population) and 16% (according to a survey on patients with cancer).[121] The survey (which was undertaken before the German advance-directive legislation came into force) has also suggested that legal clarification of the binding character of advance directives will not necessarily solve all the problems in dealing with these instruments in practice.[122] Concern was expressed by participants in the survey that that there is a lack of predictability because advance directives are often not concrete enough when they are written. The conclusion of this particular survey was that doctors must discuss more readily the contents of advance directives with their patients as well as with relatives and proxies of patients. Moreover, it was suggested that in order to improve the ethical and communicative skills of doctors, further education and institutional support should be provided.

It is said that more or less 36% of people in the United States of America have made advance directives, which is exceptionally high, compared to the jurisdictions considered above.[123] This can most probably be ascribed to other initiatives which have been introduced to enhance patient autonomy. As early as 1990, the federal *Patient Self-Determination Act*[124] was introduced by Congress with the aim of promoting greater knowledge and use of advance directives, as well as to foster respect for these documents. [125] It is stated that, apart from a commitment to patient autonomy, there were also other reasons that had driven the introduction of this act namely, the belief that more use of advance directives would reduce the amount and cost of aggressive

120 *Ibid*.
121 See Van Oorschot & Simon "Importance of the Advance Directive and the Beginning of the Dying Process from the Point of view of German Doctors and Judges dealing with Guardianship Matters: Results of an Empirical Survey" 2006 *Journal of Medical Ethics* 623.
122 Van Oorschot & Simon 2006 *Journal of Medical Ethics* 625-626.
123 See Kusmin 2006 *American Journal of Law and Medicine* 97, who relies on a survey by the website FindLaw.com. He notes that the use of advance directives is known to be highly correlated with income, race and education.
124 *Patient Self-Determination Act* codified at 42 USCA par 1395 (West 1992). The act came into effect on 1991-12-01.
125 See Olick 25.

end-of-life treatment for terminally ill and dying patients.[126] Be that as it may, the act mandates that healthcare institutions be conversant with statutory advance directive legislation and impart the content of such legislation to patients. Institutions such as hospitals, nursing facilities and hospices must inform patients of their right to participate in medical decisions and assist them to complete advance directives. However, it has been said that even these legislative imperatives have not achieved what they set out to do.[127]

Even in this day and age, people are still reluctant to undertake advance medical care planning. Apart from lack of support in this regard, this position may be ascribed also to various other reasons relating to culture and education; mistrust of doctors; ignorance and, in particular, death denial.[128] In a reflection on his own mortality by the British author Julian Barnes,[129] he refers to the views on death denial of the Russian composer, Shostakovich. The latter, who died in 1975, said that speaking of death was "tantamount to wiping your nose on your sleeve in company".[130] The music of Shostakovich, especially some of his later works, often invoke reflections on mortality. But Barnes tells us that the composer also privately expressed his views on mortality, as in the following words:

> We can't allow the fear of death to creep up on us unexpectedly. We have to make the fear familiar, and one way is to write about it. I don't think writing and thinking about death is characteristic only of old men. I think that if people start thinking about death sooner, they'd make fewer foolish mistakes.[131]

The point is also made in contemporary legal literature that people should be better informed and educated on the advanced planning of their own medical care.[132]

8 Conclusion

Core constitutional values in our society require that future non-treatment decisions be recognised as legally binding instructions. The South African Law Commission has taken various initiatives and formulated proposals for legislative reform in this regard. Like many other projects, these proposals have not borne fruit. The law relating to

126 *Ibid*.
127 See Rich 1998 *Journal of Legal Medicine* 79-80.
128 Perkins "Controlling Death: The False Promise of Advance Directives" 2007 *Annals of Internal Medicine* 51 54 observes: "Most people surely want 'dignified' care that is tailored to their wishes. However, the necessary detailed prior planning is emotionally draining, and most people lack the courage for it."
129 Barnes *Nothing to be Frightened Of* (2009) 26.
130 *Ibid*.
131 *Ibid*.
132 See Rich 1998 *Journal of Legal Medicine* 2006 78-97 and Brown 2003 *Journal of Law and Medicine* 65-68 for initiatives taken in Canada and the United States of America.

advance directives remains open to various interpretations and a culture still prevails that physicians are the exclusive arbiters of decisions relating to the continuation of a person's life in undignified and sometimes even inhumane circumstances. It is suggested that the commission's proposals be considered afresh, and tabled in parliament for debate by all interested parties.

This would be a step in the right direction. However, at a recent international exploratory workshop on advance directives doubts were raised on whether there is really a difference in the use of advance directives between countries where such instructions have legal force and those where they lack such legal force, because, "moral recognition is sometimes independent of legal status".[133] As indicated in this article, the experience elsewhere has shown that the best legislation cannot change perceptions. Health-care workers should be educated in order to enhance respect for the autonomous non-treatment decisions of patients expressed in advance directives. Patients should be informed by their physicians or, if they do not have a personal physician, by health-care workers in institutions such as hospitals and nursing homes, of their right to participate in decisions regarding future non-treatment. Persons appointed as proxies should also be fully informed of the wishes of patients as well as the implications and consequences of non-treatment decisions. In short, a holistic approach should be adopted that encourages open and frank discussion amongst physicians, patients and other interested parties on matters relating to future planning of medical care.

133 Andorno 2009 *European Journal of Health Law* 224 discusses the findings of an exploratory workshop on advance directives with participants from 19 European countries and the United States of America held at the University of Zurich in 2008. The conclusion of the group was that "the important thing, would be to disseminate information among patients about the possibility of making advance directives, and to motivate practitioners to respect patients' autonomous decisions".