

The legal validity of an advance refusal of medical treatment in South African law (part 1)

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OPSOMMING

Die Regsgeldigheid van 'n Gebeurlikheidsweiering van Mediese Behandeling in die Suid-Afrikaanse Reg

Mediese tegnologie het sodanig ontwikkel dat dit vandag moontlik is om die lewe van 'n persoon byna onbepaald te verleng in omstandighede waarin hy of sy andersins 'n natuurlike dood sou sterf. Sommige mense verkies om sodanige behandeling te vermy, onder meer omdat hulle met waardigheid wil sterf.

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 van sodanige gebeurlikheidsaanwysing onseker. 'n Oorweging van grondwetlike kernwaardes dui egter daarop dat mediese gebeurlikheidsaanwysings in beginsel as regtens afdwingbare wilsbesluite erken behoort te word. In die eerste gedeelte van hierdie bydrae word die huidige regsposisie en die etiese norme wat in die mediese beroep geld, bespreek. Die toepaslike grondwetlike kernwaardes word dan ontleed en teen bepaalde belange van die gemeenskap opgeweeg. 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 gebeurlikheidsaanwysing in bepaalde omstandighede as regtens afdwingbaar beskou behoort te word. Die ontwikkeling 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 studie lei tot die gevolgtrekking 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 gebeurlikheidsaanwysings 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. 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 groter bewuswording van die reg op selfbeskikking van pasiënte by gesondheidsorg-werkers sowel as die breë publiek te bewerkstelling.

1 Introduction

The most challenging goal of medical science has always been to sustain life or, to put it differently, to postpone the onset of death. Before the 20th century, this was mostly unattainable but from the middle of the 20th century, there have been extraordinary advances in life-sustaining medical technologies which have contributed significantly to the prolongation of human life. To mention just a few: in 1930 insulin was developed to control diabetes; in 1931 the ventilator was introduced and in the 1950s open-heart surgery was performed for the first time. Cardiopulmonary resuscitation was introduced in the 1960s and has been routinely performed ever since. Coronary artery bypass surgery, kidney transplants, chemotherapy and hospital intensive care units have become commonplace as well.¹ Today, the development of new ways to prolong life remains the priority of medical science. This has made a huge difference to the life expectancy of human beings with, in many cases, added quality of life. But, unfortunately, it is possible to prolong life without any benefit to the patient. Whereas death used to be seen as a natural event determined by fate or an “act of God”, decisions must be made today on whether a person can be regarded as “legally” dead (in other words, brain dead)² and if not, whether life should nevertheless be prolonged by artificial means in cases where there is no hope or reasonable prospect of recovery. For instance, technological advances in intensive care units have enabled more elderly patients to survive acute critical illness. It has actually been said that these advances have “created a new population who are chronically critically ill”.³ Such patients may have persistent respiratory failure, dysfunction of other organs and complications such as recurrent infections and pressure ulcers. Prolonged mechanical ventilation is often required to keep them alive. Sadly, the outcome of the treatment of patients with chronic critical illness is usually death shortly after discharge from hospital or total dependence requiring long-term custodial care. Long-term dependence imposes a heavy burden on patients, their families, caregivers and the healthcare systems, which incur enormous costs.

1 King *Making Sense of Advance Directives* (1991) 32; Kruse “A Call for New Perspectives for Living Wills (you might like it here)” 2002 *Probate and Trust Journal* 545 546-549.

2 In terms of s 1 of the National Health Act 61 of 2003 the moment of death is defined as “brain death”, which is defined as “an irreversible and irreparable cessation of all the brainstem functions inclusive of complete cessation of the heartbeat, respiration, blood circulation and digestive functions” Carstens and Pearmain *Foundational Principles of South African Medical Law* (2007) 204 n 433. This definition of death is accepted in other jurisdictions as well but defining death remains problematic and controversial. See Herring *Medical Law and Ethics* (2010) 464-469 for a discussion of alternative definitions of death.

3 Camhi, Mercado, Morrison, Du, Platt, August and Nelson “Deciding in the Dark – Advance Directives and Continuation of Treatment in Chronic Critical Illness” 2009 *Critical Care Medicine* 919.

The question that arises is: Who should take the decision to withdraw or withhold treatment in medically futile situations? Should it be the doctor, who is generally perceived to know best, or should the wishes of the family prevail? What about the patient? Should the overriding concern not be what the patient would have wished had he or she been able to make the decision? What is the position if the patient has given a specific written or oral instruction, while still competent, that he or she does not want to be kept alive by artificial means in such circumstances, or in a similar condition? These questions have been debated elsewhere and, to a lesser extent, in South Africa as well. The traditional assumption, namely that that these questions should be answered by applying medical standards only, has been challenged by lawyers and ethicists, particularly during the last decades. It is now generally accepted that questions relating to the foregoing of medical treatment are not only questions of medical science, but also questions rooted in law and ethics. In many jurisdictions the rules of conduct for physicians are no longer restricted to the application of medically-accepted standards. They also comprise of legal and ethical norms such as respect for patient autonomy.

The shift in emphasis from medical paternalism to recognition of patient autonomy has given rise to drastic changes in the law relating to medical practice. In most constitutionally-grounded jurisdictions it has been accepted also that there is a need for legal recognition of a means of some kind to enable people to exercise control over their bodies once they are no longer able to communicate their medical preferences. Such control may be achieved by an instruction by a competent person regarding his or her future medical treatment. Generally referred to as advance directives, such instructions can take two different forms which are not necessarily exclusive of each other: Living wills and enduring powers of attorney for healthcare. Living wills (also referred to as instructional advance directives) are written documents designed to allow people to express their preferences regarding the withholding of specified treatments if at any time in the future they are no longer able to take such decisions.⁴ The lasting power of attorney (also referred to as a “proxy directive”) allows an individual to appoint someone else as a health care proxy (for example, a trusted friend or relative) to make health care decisions on his or her behalf.

The legal status of advance medical directives in South African law and the validity of such directives in terms of various constitutional imperatives and ethical concerns are the main issues considered in this article. As an introduction, the legal status of a contemporaneous

4 Brown “The Law and Practice associated with Advance Directives in Canada and Australia: Similarities, Differences and Debates” 2003 *Journal of Law and Medicine* 59 60 points out that the first “living wills” were letters that individuals wrote to their families and loved ones stating that they would not want to have their life extended artificially if they were no longer competent to make these decisions for themselves.

decision to refuse medical treatment is first described. This is followed by a discussion of the current legal status of a prospective decision to refuse medical treatment. The current legal position is then compared with the medical approach – the guidelines to health care practitioners which apply internally in the medical profession. The relevant constitutional values are then discussed and balanced against various counter-interests of the community and the state. In the follow-up article various ethical concerns regarding the exercise of prospective autonomy are raised. This is followed with a discussion of the legal status of advance medical directives in other legal systems. Problems encountered in these jurisdictions with the enforcement of advance medical directives and the steps taken to address these problems are highlighted with a view to deal effectively with similar problems which may be encountered here.

2 The Legal Status of a Contemporaneous Decision to Refuse Medical Treatment

In South Africa the common law is clear on the legal status of a contemporaneous decision. People with decisional capacity may refuse life-sustaining medical treatment with regard to an illness or injury from which they may be suffering even though such a refusal may hasten their death. In *Castell v De Greeff*⁵ it was confirmed that the right stems from the person's fundamental right to self-determination, which includes the right to bodily integrity and that it relates to the doctrine of informed consent which recognises the autonomy of the patient to make decisions regarding whether he or she wishes to receive or does not wish to receive medical treatment. The idea that consent may render an act not unlawful is treated in South African law as falling under the defence of *volenti non fit iniuria*, the enquiry being whether the said defence has been established and, in particular, whether the patient's consent has been a properly informed consent.⁶ In terms of the doctrine of informed consent, physicians must inform their patients about the material risks and benefits of recommended treatment and the patient must decide whether to undergo the treatment or not.⁷ What is more, the patient's judgment of his or her interests is decisive and, as pointed out by Ackerman J in *Castell v De Greeff*:⁸

It is, in principle, wholly irrelevant that her attitude is, in the eyes of the entire medical profession, grossly unreasonable, because her rights of bodily integrity and autonomous moral agency entitle her to refuse medical treatment.

For instance, if a person refuses to undergo a blood transfusion for religious reasons, his or her decision must be respected, even if he or she

5 *Castell v De Greeff* 1994 4 SA 408 (C) 420J; 422 H-J, citing Van Oosten *The Doctrine of Informed Consent in Medical Law* (LLD dissertation 1989 UNISA) 414.

6 420H-J; 425H-1.

7 Van Oosten 414.

8 421C.

will die as a result of the refusal. Thus, for the refusal of treatment to have legal force the patient must have had the capacity to refuse treatment and such refusal must be based upon essential knowledge regarding the nature and effect of the proposed refusal.⁹

3 The Legal Status of a Prospective Decision to Refuse Medical Treatment

When the patient has lost his or her capacity to make a decision to undergo or refuse treatment, the question arises whether an instruction to refuse medical treatment should be honoured if given by the patient at some time in the past while he or she still had the mental capacity to make a decision. For instance, the patient may have issued an instruction in a “living will” refusing specific treatment should he or she become incompetent to do so. Living wills do not fall under the Wills Act,¹⁰ which only covers testamentary dispositions, nor are they recognised explicitly by any other statute. Further, there is no direct authority at common law on the legal validity of a “living will”. The only decision in which a so-called “living will” featured was *Clarke v Hurst*.¹¹ Dr Clarke, while undergoing an epidural block, suffered cardiac arrest after a sudden drop in blood pressure. His heart stopped beating and he stopped breathing. Had he not been resuscitated, he would have died. His heartbeat and breathing were restored but by that stage he had suffered irreversible brain damage and was diagnosed as being in a permanent vegetative state.¹² He was unable to take food and was artificially fed through a nasogastric tube. After the patient had been in this state for four years, his wife applied to the court to be appointed as curatrix. She sought authority to agree to or withhold agreement to any medical treatment for him; to authorise the discontinuance of any present or future treatment

9 McQuoid-Mason “The Legal Status of the ‘Living Will’ 1993 *Continuing Medical Education* 59; McQuoid-Mason “Pacemakers and Living Wills: Does turning down a Pacemaker to allow Death with Dignity constitute Murder?” 2005 *SACJ* 24 27. The theoretical premise is of course, not always similar to the *de facto* position in practice. As pointed out by Biggs *Euthanasia, Death with Dignity and the Law* (2001) 103 many patients give or refuse consent without fully understanding the implications of the medical intervention or treatment that is proposed. Patients do not always understand the language used by physicians which presupposes a good knowledge of the workings of the human body. Many patients also blindly trust their physicians to know better than they do as to what is in their best interest.

10 Wills Act 7 of 1953.

11 1992 4 SA 630 (D).

12 A permanent vegetative state was explained by Thirion J in *Clarke v Hurst* 1992 4 SA 630 (D) 640D-F as “a neurological condition where the subject retains the capacity to maintain the vegetative part of neurological function but has no cognitive function. In such a state the body is functioning entirely in terms of its internal controls. It maintains digestive activity, the reflex activity of muscles and nerves for low level and primitive conditioned responses to stimuli, blood circulation, respiration and certain other biological functions but there is no behavioural evidence of either self-awareness or awareness of the surroundings in a learned manner”.

including the discontinuance of any nasogastric feeding or hydration regime; and to act within these powers, despite the fact that the implementation of her decisions might hasten the death of the patient. The order as sought was granted and a week later the patient died.

At the hearing, evidence was led to the effect that Dr Clarke was a life member of the South African Voluntary Euthanasia Society (SAVES). He had signed a living will directing that should he in the future contract a terminal illness with no hope of recovery or become permanently unconscious, he should not be kept alive by artificial means but be allowed to die. He had even delivered a public speech in favour of the right to die in certain circumstances.¹³ On the basis of this evidence, Thirion J recognised that there was a strongly held conviction on the patient's part that should he ever be in the kind of condition in which he had been since the cardiac arrest, no effort should be made to sustain his life by artificial means but he should be allowed to die.¹⁴ But the court did not base its decision on these instructions by the patient nor did it rule on the validity of the "living will". Instead, Thirion J ruled that the discontinuance of an artificial feeding regime would not be the legal cause of the death,¹⁵ that in terms of the legal convictions of society, it would not be wrongful or unlawful to discontinue any medical treatment or artificial feeding regime previously administered to the patient that had merely kept his body alive¹⁶ and that it would be in the patient's best interests to permit him to die.¹⁷ The court added that although the patient had passed beyond the point where he could be said to have an interest in the matter, his wishes as previously expressed when he was competent should be given effect to, just as a living person has an interest in the disposal of his body.¹⁸ It is beyond dispute, however, that this case does not provide any authority for recognition of the legal validity of a living will.¹⁹

In 1992, an effort was made by the South African Law Commission to address, *inter alia*, this lacuna in our law. The commission initiated a research project on euthanasia, the artificial preservation of life and related issues such as the need for legal recognition of advance directives. In response to widespread public support, draft legislation was

13 633J-A.

14 633J-634A.

15 660B-C. The court based its finding on the more flexible criterion for legal causation introduced in *S v Mokgethi* 1990 1 SA 32 (A), namely whether policy considerations of reasonableness, fairness and justice require that an act is viewed as the legal cause of a result.

16 653-657.

17 660D-F.

18 660E.

19 Strauss "The 'right to die' or 'passive euthanasia': Two Important Decisions, One American and the Other South African" 1993 *SACJ* 196 208 who regrets the court's reluctance to give explicit recognition to living wills; Fleischer "End-of-life Decisions and the Law: A New Law for South Africa?" 2003 (21) *Continuing Medical Education* 20; McQuoid-Mason 59.

proposed by the commission in 1998²⁰ which authorises health care practitioners to honor advance directives – a living will or medical power of attorney prepared by a patient when he or she was competent. The relevant recommendation²¹ provides that any person above the age of eighteen may, if of sound mind, make an advance directive by signing either a living will that directs withholding or withdrawing any medical treatment when a patient has a terminal illness or a power of attorney to appoint a surrogate to make medical decisions if the patient becomes incompetent and terminally ill. An advance directive may be honoured only if doctors decide the patient cannot make or communicate decisions and has a “terminal illness” which is defined as either a permanent vegetative state (pvs) or any condition that will inevitably cause “untimely death” and cause the patient “extreme suffering”. It is beyond the scope of this article to indulge in a critical analysis of these recommendations. Suffice it to say that since 1998, the proposed law has been in the hands of the Minister of Health, who has the authority to forward it, or a revised version, to parliament for enactment. This has not as yet taken place and is clearly not regarded as a priority.

Therefore, the current legal position is that advance directives in the form of “living wills” are not recognised as legally enforceable instructions by either statute or common law. But legal academics argue that since an instruction in a “living will” is merely an instruction to refuse medical treatment in the future, the principles governing a contemporaneous refusal of treatment by a patient would also apply to situations where a patient makes an advance directive in a living will. The first legal writer who considered the need to recognise the legal validity of a living will in South Africa was Strauss.²² Even before the judgment in *Clarke*,²³ Strauss argued that if a person is entitled to refuse medical treatment when it is proposed that he or she should immediately receive such treatment, there is no reason why he or she should not be entitled to express a standing refusal at an earlier stage. Such a refusal, if properly recorded, would stand until revoked by the person who made it.²⁴ Strauss added that doctors and hospital staff must respect the declarant’s statement of refusal and that should a doctor disregard it and keep the patient alive by artificial means, the doctor would, in his opinion, be “technically” guilty of assault in both civil and criminal law.²⁵ This point of view is still accepted by other experts on medical law.²⁶

20 South African Law Commission “Report on Euthanasia and the Artificial Preservation of Life” (1998) RP 186/1999.

21 In the “Summary of Recommendations” of the report. For critical discussions of the recommendations, see Landman “Legalising Advance Directives in South Africa 2000 *SA Medical J* 785 786-787; Fleischer 22-25.

22 Strauss *Doctor, Patient and the Law: A Selection of Practical Issues* (1984) 387.

23 *Clarke v Hurst* 1992 4 SA 630 (D).

24 Strauss 344-345.

25 345.

26 McQuoid-Mason 2005 *SACJ* 27-28; Carstens and Pearmain 209; Burchell *Principles of Criminal Law* (2006) 328.

But what is the position if a person, in an advance directive, appoints another person to consent to or refuse medical treatment on his or her behalf once he or she becomes incompetent? In terms of the common law, an enduring power of attorney becomes invalid when the patient becomes mentally incompetent. But certain provisions of the National Health Act 61 of 2003 may provide grounds for arguing that advance directives in the form of enduring powers of attorney must be honoured by health care practitioners. Some of these provisions, although stated in very general terms, also add weight to the argument that “living wills” should be accorded legal validity.

Section 7(1)(a) of the Act provides:

Subject to section 8, a health service may not be provided to a user without the user’s informed consent, unless - (a) the user is unable to give informed consent and such consent is given by a person – (i) mandated by the user in writing to grant consent on his or her behalf.

Section 7(1)(e) further states that a health service may not be provided to a user without the user’s informed consent unless

any delay in the provision of the health service to the user might result in his or her death or irreversible damage to his or health and the user has not expressly, impliedly or by conduct refused that service.²⁷

McQuoid-Mason interprets section 7 as providing a possible mechanism for overcoming the common-law problem of enduring powers of attorney becoming invalid if patients become mentally incompetent.²⁸

Regrettably, the provisions of section 7 are subject to section 8 of the Act, which is rather confusing. Section 8(1) clearly provides: “A health care user has the right to participate in any decision affecting his or her personal health and treatment.” Section 8 (2)(a) provides further that if the informed consent required by section 7 is given by a person other than the user, “such person must if possible consult the user before giving the required consent”. The words “if possible” indicate that the act recognizes that consultation *may not be possible* because the health care user was mentally incompetent at the time the consent was required.²⁹ But then section 8(3) provides that if a user is unable to participate in a decision affecting his or her health and treatment, he or she must be given full information on the treatment received after the provision of the health service. There is no reference to “if possible” in this section. It could therefore be argued that there is an expectation that the patient will *not* be permanently incompetent and that the information should be provided on his or her recovery.

27 The rest of s 7 sets out a hierarchy of persons who may consent on behalf of the user if he or she is unable to consent and no person has been mandated or authorised to give such consent.

28 McQuoid-Mason “Advance Directives and the National Health Act” 2006 *SA Medical J* 1236 1237.

29 See the views of McQuoid-Mason 1237.

The act therefore contains provisions which, if interpreted broadly, could provide the basis for arguing that an advance directive in the form of an enduring power of attorney made by a patient while competent attains legal validity once the patient becomes incompetent. The question that arises is that, if such powers of attorney are legally enforceable instructions, should the same legal status not be afforded to advance directives in the form of “living wills”? Living wills are not expressly recognised in the act, but section 8(1) makes it clear that a health care user has the right to participate in *any* decision affecting his or her personal health and treatment. Does this mean that a decision to refuse medical treatment in the future has the same legal validity as a contemporaneous decision? In view of the absence of clear and express recognition at common law or statute of the legal status of advance directives, this remains an open question.

4 The Position in Medical Practice

Until recently, there were also no specific guidelines for health care practitioners to follow if confronted with living wills. But in 2008, the Health Professions Council of South Africa took a great step forward by creating ethical guidelines for health care practitioners.³⁰ The predominant ethical principle that underpins these guidelines is that of patient autonomy. In the introduction to these guidelines, it is stated that to establish mutual trust between health care practitioners and patients, practitioners must respect patients’ autonomy, for instance, their right to refuse treatment even if it may result in harm to themselves or in their own death.³¹ It is emphasized that the right to an informed consent flows, *inter alia*, from the South African Constitution, the National Health Act and the common law. It is also stated that patients have a right to information regarding their condition and the treatment options available and that sufficient information should be given to patients by means of effective communication.³²

Firstly, the guidelines assume that the provisions of the National Health Act 61 of 2003 allow patients to give a written mandate to a person to act on their behalf when they are no longer able to do so.³³ Secondly, the Health Professions Council of South Africa suggests that patients should be encouraged to appoint in writing a person to make decisions on their behalf when they are no longer capable of doing so,³⁴ and that patients should be given the opportunity and be encouraged to indicate their wishes regarding further treatment and to place in writing their directives for future care in possible critical circumstances (for example, permanent coma or terminal illness). A further suggestion is

30 Health Professions Council of South Africa (HPCSA) *Guidelines for Good Practice in the Health Care Professions* (2008) booklet 12 “Guidelines for the Withholding and Withdrawing of Treatment”.

31 Par 2.1 of booklet 9.

32 Par 2.3 and 3.11 of booklet 9.

33 Par 2.1 of booklet 12.

34 Par 2.1.

that an appropriately drafted “living will” could be used for this purpose.³⁵ The guidelines recognise that these instructions can also be contained in a mandate to a third party.³⁶ It is also recommended that patients should be given the opportunity to reconsider and alter their directives from time to time.³⁷

A further paragraph, which deals with “making decisions for the patient” states that “[w]here a patient lacks the capacity to decide, health care practitioners must respect any valid advance refusal of treatment”.³⁸ It is significant that the circumstances in which a health care practitioner *must* respect any valid advance refusal of treatment are not explicitly limited to cases of a permanent vegetative state or terminal illness. The fact that these ethical guidelines apply in medical practice shows that the law is not in accordance with generally accepted medical practice. Of even greater significance, however, is the discrepancy between other laws and the South African Constitution.

5 The Relevant Constitutional Values

Decisions to refuse medical treatment in the future engage certain fundamental human rights which should be balanced against various interests of the community. The constitutional imperatives which are of particular significance for our purposes are: the right of the person to preservation of his or her dignity;³⁹ the right to freedom and security of the person, in particular the right to bodily integrity;⁴⁰ the right to

35 Par 2.3.

36 Par 2.3.

37 Par 2.3.

38 Par 8. Of course in the case of children it is required that their decisions to refuse health care should be respected, provided they have legal capacity to make such decisions and it is in the child’s best interests. If the practitioner believes that such refusal is not in the child’s best interests, he or she should approach the court for a decision. See par 14 of booklet 12 of the HPCSA guidelines.

39 S 10 of the Constitution provides: “Everyone has inherent dignity and the right to have their dignity respected and protected”. Currie and De Waal *The Bill of Rights Handbook* (2008) 272 describe “human dignity” as “a central value of the ‘objective normative value system’ established by the Constitution, perhaps the pre-eminent value” (citing the Constitutional Court in *Carmichele v Minister of Safety and Security* 2001 4 SA 938 (CC) par 56). These writers point out that the origins of the concept can be traced to Kantian moral values according to which human dignity gives a person intrinsic worth. In *S v Dodo* 2001 3 SA 382 (CC) par 38 Ackerman J emphasised that “[h]uman beings are not commodities to which a price can be attached, they are creatures with inherent worth and infinite worth; they ought to be treated as ends in themselves, never merely as means to an end”.

40 S 12(2)(b) provides: “Everyone has the right to bodily and psychological integrity which includes the right to security and control over their body”.

privacy;⁴¹ the right to life and the right to equality and freedom from discrimination.⁴²

Clearly the right to bodily integrity and the right to dignity provide the bases for arguing that the patient has a right to refuse medical treatment.⁴³ The famous words of John Stuart Mill⁴⁴ that “the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others” is of particular significance in the context of refusal of medical treatment. The core value of self-determination is arguably equally valid in respect of both contemporaneous and prospective refusal of medical treatment. A patient does not lose his or her autonomy and more specifically his or her right to bodily integrity because of possible loss of decisional capacity in the future. Even if it is argued that the rights of competent persons to refuse medical treatment in the future is not derivative of those of competent persons who refuse medical treatment in a contemporaneous setting, the claim to exercise “future-oriented rights” deserves consideration.⁴⁵

In the literature, the concept of autonomy has been addressed mainly in the context of the exercise of choices in a contemporaneous setting. However, Dworkin has made an important contribution in explaining the ethical foundations of prospective autonomy in the context of refusal of medical treatment. He distinguishes between the “critical interests” and “experiential interests” of a person.⁴⁶ Critical interests reflect a person’s sense of identity and the lived narrative that gives rise to his or her values. However, mere experiential interests are more related to the satisfaction of immediate experience and the activities of daily living – a

41 S 14 provides that everyone has the right to privacy, which shall include the right not to (a) have their person or home searched; (b) their property searched (c) their possessions seized; or (d) the privacy of their communications infringed.

42 The relevant parts of s 9 provide that (1) everyone is equal before the law and has the right to equal protection and benefit of the law; (2) that to promote the achievement of equality, legislative and other measures designed to protect or advance persons, or categories of persons, disadvantaged by unfair discrimination may be taken and (3) that the state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including, race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth and (4) that national legislation must be enacted to prevent or prohibit unfair discrimination.

43 Van Oosten 441 states that “the cardinal principle of self-determination still demands that the ultimate and informed decision to undergo or refuse [a medical] intervention should be that of the patient and not that of the doctor” (cited in *Castell v De Greeff* 422J-423A).

44 Gray and Smith (eds) *JS Mill ‘On Liberty’ in Focus* (1991) 30.

45 Olick *Taking Advance Directives Seriously* (2001) 46 defends “a deeper claim about the importance of the principle of prospective autonomy”. He argues that “future-oriented decisions are integral to the life of autonomous persons, no less concerning the way we die than the way we live”.

46 Dworkin *Life’s Dominion: An Argument about Abortion, Euthanasia and Individual Freedom* (1993) 200-213.

person's enjoyment of concrete aspects of life such as listening to music; enjoying a good meal or dislike of certain other activities such as sport. Dworkin argues that the values in society, such as autonomy and dignity, require us firstly to respect the *critical interests* of a person. The lack of control over one's own destiny (including one's own death) essentially involves loss of autonomy and possible loss of dignity. The paramount concern of a person who refuses medical treatment through an advance directive is to preserve his or her capacity to control his or her own life and to preserve his or her dignity. Therefore, argues Dworkin, advance directives should be obeyed because it presents a person's "critical interests" namely, how to live and how to die.

The right to dignity and the right to self-determination also inform the right to privacy. This right guarantees the individual the freedom to make certain fundamentally private choices without state interference, including choices about how to lead his or her own life.⁴⁷ It is submitted that such a choice includes the decision to refuse medical treatment, which may also be expressed in an advance directive.

The right to equality is relevant as well. According to South African equality jurisprudence, differentiation between people that amounts to unfair discrimination is prohibited. If the differentiation is on certain specified grounds, such as age, disability or religion, discrimination as such will be established. If not, the enquiry into discrimination will examine whether the ground is based on attributes and characteristics that have the potential to impair the fundamental human dignity of persons as human beings.⁴⁸ It may be argued that to allow a person to refuse medical treatment in a contemporaneous decision, and to disallow a person from making an advance directive to forego medical treatment should he or she become incompetent in future, amounts to discrimination on the basis of one of the specified grounds, namely "disability". But even if this argument fails, a case for unfair discrimination can nevertheless be made out. In *Brink v Kitshoff*⁴⁹ the Constitutional Court subscribed to a substantive concept of equality which requires the law to ensure equality of outcome and not only to treat persons in the same circumstances alike, as required by the concept of formal equality.⁵⁰ In other words, even if it may be argued that patients who refuse medical treatment in future by means of advance

47 In *Bernstein v Bester* 1996 2 SA 751 (CC) par 67 Ackerman J stated that it would be reasonable to expect privacy "in the inner sanctum of a person ..." that lies in the "truly personal realm...". He also referred (par 73) to the Council of Europe's view of the right to privacy, namely that it "consists essentially in the right to live one's own life with a minimum of interference".

48 *Harksen v Lane* 1988 1 SA 300 (CC) par 53.

49 1996 6 BCLR 752 (CC) paras 41-44.

50 See also Currie and De Waal *Bill of Rights Handbook* (2008) 233: "Formal equality means sameness of treatment: the law must treat individuals in like circumstances alike. Substantive equality requires the law to ensure equality of outcome ..."

directives are not in the same position as patients who refuse medical treatment in a contemporaneous decision, the equality guarantee is violated if the law denies both categories of persons the same outcome.⁵¹

The fundamental rights identified must, however, be weighed against counter-interests of society. It has been argued in other jurisdictions that the “potential interests” of a foetus to be born alive should be considered before giving effect to the wishes of a pregnant patient to refuse medical treatment, irrespective of whether such wishes were expressed in a contemporaneous decision by a competent patient or at a previous stage in an advance directive.⁵² In South African law, a foetus is not regarded as a “person vested with rights such as a constitutional right to life.”⁵³ But

51 Olick 13: “Equating the rights of incompetent patients with those of competent patients also embraces the law’s long-standing commitment to equality and to protection of disabled and vulnerable persons from discrimination and abuse. The value of human dignity and worth extends to all persons equally, not just to competent and healthy persons. To conclude otherwise would ... do violence to incompetent patients’ interests in self-determination ...”

52 In the United States treatment has been forced on unwilling pregnant patients on grounds such as “the unborn child’s right to live and “the state’s compelling interest in preserving the life of the foetus” (*Jefferson v Griffin Spalding County Hospital Authority* (1981) 274 SE 2d 457). Currently, a majority of the states have legislation which specifically addresses the status of an advance directive of a pregnant but incompetent woman. The legislation varies considerably. In seventeen of the states, advance directive of pregnant women have no binding effect irrespective of the stage of development of the foetus. In other states a balance between the constitutional rights of an incompetent woman and the interest of the state to protect potential life is sought by criteria such as the “probability” that the foetus will develop to live birth if the treatment is administered. Pregnancy clauses have not been found to be unconstitutional under United States jurisprudence. See Sperling “Do Pregnant Women have (living) will?” 2005 *Journal of Health Care Law and Policy* 331 336-340. He argues (333) that since there is no specific provision which deals with the status of advance directives of pregnant women in Canadian law, it seems as if “Canadian law treats the incompetent pregnant woman who issued an advance directive while competent the same way as it treats other incompetent patients, that is, it respects the patient’s right to control her medical decisions”. The South African Law Commission also did not consider this particular issue in its “Report on Euthanasia and the Artificial Preservation of Life”. In the United Kingdom, absolute value is attached to the right of a competent pregnant woman to refuse medical treatment even if she is in the final stages of pregnancy and her own life and that of the unborn child depend on such treatment and even if her decision appears “morally repugnant” (*St George’s Healthcare NHS Trust v S* [1998] 3 All ER 673 692a-c). There is also no provision in the United Kingdom legislation (*The Mental Capacity Act 2005*) that an advance directive refusing life-saving treatment would not apply if the patient were pregnant with a viable foetus. Therefore, an advance refusal would be regarded as enforceable in such circumstances, provided that the advance directive is clear and there is no reason to believe that the patient did not anticipate that she would be pregnant at the crucial time. (See s 25(4) of the *Mental Capacity Act 2005*.)

53 See *Christian Lawyers’ Association v Minister of Health* 2004 10 BCLR 1086 (T); *S v Mshumpa* 2008 (1) SACR 126 (E) par 56; *Road Accident Fund v Mtati* 2005 6 SA 215 (SCA).

in terms of the Choice on Termination of Pregnancy Act,⁵⁴ it is an offence for a medical practitioner to perform an abortion after the 20th week of pregnancy if the mother's life is not in danger or there is no danger of serious malformation of the foetus. Because *some value* is attached to the interests of a well-developed foetus, it may be argued that these interests should at least be considered and balanced against the interests of the incompetent mother who made an advance directive refusing medical care. In the United States of America, the courts have also limited the right of self-determination expressed in a contemporaneous decision if necessary to protect public health.⁵⁵ It is submitted that the right to refuse medical treatment may be challenged on this ground in the context of the exercise of prospective autonomy as well.

Can the principle of prospective autonomy also be challenged on the basis of a general state interest in preserving life? Section 11 of our Constitution merely provides that “[e]veryone has a right to life”. In *S v Makwanyane*⁵⁶ the Constitutional Court held that the death sentence violated the right to life, which includes the right “not to be deliberately killed by the state through a systematically planned act of execution sanctioned by the State as a mode of punishment ...”.⁵⁷ But what is the significance of the right to life in the context of refusal of medical treatment in an advance directive? It is submitted that the unqualified nature of the right to life in the Constitution certainly provides for an interpretation of the concept of “life” as something more than merely physical existence – signifying at least a certain *quality of life*. In *Makwanyane*, O’Regan J emphasised the interrelationship between the right to life and the right to dignity as follows:⁵⁸

The right to life was included in the Constitution not simply to enshrine the right to existence. It is not life as mere organic matter that the Constitution cherishes, but the right to human life: the right to share in the experience of humanity ... the rights to human dignity and life are entwined. The right to life is more than existence – it is the right to be treated as a human being with dignity: without dignity, human life is substantially diminished ...

54 S 2(c)(i) and s 2(c)(ii) of the Choice on Termination of Pregnancy Act 92 of 1996.

55 See Neeley *The Constitutional Right to Suicide: A Legal and Philosophical Examination* (1994) 148, citing *Jacobson v Massachusetts* 197 U.S. 11 (1905).

56 1995 3 SA 391 (CC).

57 Par 269.

58 Paras 326-327. Singer “Rethinking Life and Death” (1994) 75 argues that in the contemporary age considerations as to the *quality* of life are an inherent feature of medical practice. Dworkin 210 emphasises, however, that it is not every kind of dependent life of a person with a severe handicap that is not worth living. He refers, for example to the meaningful life of the brilliant scientist Stephen Hawking and millions of other ordinary people who lead valuable lives despite being handicapped. But, in his view (210) “[t]otal or near-total dependence with nothing positive to redeem it may seem not only to add nothing to the overall quality of a life but to take something important from it.” This is particularly the case where there is no comprehension that care is given.

English legal writers and philosophers have considered the meaning of concepts such as “quality of life and “sanctity of life”.⁵⁹ According to Herring, sanctity of life seeks to value the good of life itself independent of any disability or incapacity. Quality of life is concerned with the assessment of the worthwhileness of the patient’s life and rejects the argument that there is something good about life in itself. Huxtable refines this explanation. He distinguishes between the “intrinsic value of life”; the “instrumental value of life” and the “self-determined value of life.”⁶⁰ The concept “intrinsic value of life” means that life is sacred and absolutely inviolable, to the extent that every attempt should be made to preserve life. But, as Huxtable points out, the doctrine is not absolute since it does allow life to be ended in some situations such as killing in self-defence.⁶¹ In terms of the concept “instrumental value of life” the absolute value of life itself is not the fundamental consideration. The “quality of life” also comes into play. For instance, a decision of a court of law that it would not be unlawful to withdraw treatment from a person in a permanent vegetative state who has no quality of life left, would rather be grounded in the *instrumental* value of life. The concept “self-determined value of life” is based on the principle of respect for patient autonomy. The individual determines the value of his or her life.⁶² It is submitted that the right to refuse medical treatment by way of an advance directive gives effect to the idea of “quality of life” in the sense of *self-determined* value of life.

But could it nevertheless be argued that the state has a general interest in the preservation of life which deserves to be balanced against the patient’s right to autonomy? King distinguishes between the societal value of prevention of suicide (in limited circumstances) and the broader societal value of the preservation of life.⁶³ She argues that refusal of treatment which hastens death is not viewed as suicide because:

the patient does not wish to die, but rather does not wish to live under the conditions of treatment – and therefore accepts death only as the outcome of his or her refusal of burdensome treatment.⁶⁴

59 Herring 499-501; Huxtable *Euthanasia, Ethics and the Law: From Conflict to Compromise* (2007) 133-140.

60 Huxtable 133-140.

61 *Idem* 136-137.

62 *Idem* 11 and 135.

63 King 47 argues that although an attempt to commit suicide is no longer punishable, prevention of suicide is a legitimate beneficent concern in cases where the would-be suicide lacks the mental capacity to make an autonomous decision. She points out, however, that American courts have held that prevention of suicide is not a legitimate societal concern in cases of refusal of medical treatment.

64 I 47 gives the example of a Jehovah’s witness who refuses blood not in order to die but in order to avoid damnation. Likewise, patients who refuse to stay on artificial respiration do not necessarily wish to die. Herring 476 explains that the general view is that “suicide involves a person intentionally killing themselves”. If the patient refuses treatment because he or she wants to die then it could be viewed as suicide, but if the patient’s act is not prompted by

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But there is also a broader societal interest in the preservation of life which largely relates to the principle that all human life should have equal value. If a decision to refuse medical treatment has the effect of devaluing others' lives, the value of autonomy should yield to the state's interest in the preservation of life.⁶⁵ The interest of the state in safeguarding the notion of the sanctity of life features prominently in the debate on whether voluntary active euthanasia should be legalised. In that context, it is argued that to allow physicians to actively participate in terminating their patients' lives at their request potentially devalues the lives of other, vulnerable members of society.⁶⁶ But this argument appears to be too broad in the context of mere refusal of medical treatment. It would seem to be remote and unreasonable to require that a person forfeit his or her right to refuse medical treatment in the general interest of society in respecting the sanctity of life.⁶⁷

The constitutional analysis demonstrates that law reform, whether via development of the common law⁶⁸ or through legislation is required. But recognition of the legal validity of the advance directives does not mean that such directives should be honoured in all circumstances. There are

the desire to kill herself or himself (even if death is foreseen) then the act is permissible. But Herring 541 points out that there may be cases where a patient refuses treatment with the purpose of committing suicide. He gives the example of a teenager who has a septic cut and refuses treatment because he has been disappointed in love. But in such instances where the decision is assessed by the courts as "utterly unreasonable" the patient is declared incompetent.

- 65 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 *Behavioral Sciences and the Law* 253 257 cites the case of *Superintendent of Belchertown State School v Joseph Saikewicz* 370 NE 2d 417 426-427 (1977) in support of his statement that American courts "rarely find that state interests [such as preservation of life] are sufficiently compelling to deny an individual's right to refuse medical treatment".
- 66 Proponents of this argument are, *inter alia*, Keown *Euthanasia, Ethics and Public Policy – An Argument against Legalisation* (2002) 37-80 and Amarasekara and Bagaric "Moving from Voluntary Euthanasia to Non-Voluntary Euthanasia: Equality and Compassion" 2004 *Ratio Juris* 398.
- 67 *Cf* the views of Porter "Advance Directives and the Persistent Vegetative State in Victoria: A Human Rights Perspective" 2005 *Journal of Law and Medicine* 256. She points out (261-262) that the right to life is concerned with the prevention of arbitrary taking of life which is a threat to the existence of society and that it is not violated where a person is allowed to die following the withdrawing or withholding of treatment in accordance with a person's previously expressed wishes.
- 68 S 39(2) of the Constitution of the Republic of South Africa, 1996 provides that a court, when developing the common law, must promote the spirit, purport and objects of the Bill of Rights. Since the inception of the Constitution the Constitutional Court and the Supreme Court of Appeal have ruled in a number of cases that the common law should be developed in terms of these values, norms and objects. See *Carmichele v Minister of Safety and Security* 2001 4 SA 938 (CC); *Van Eeden v Minister of Safety and Security* 2003 1 SA 389 (SCA); *Minister of Safety and Security v Van Duivenboden* 2002 6 SA 431 (SCA); *Minister of Safety and Security v Hamilton* 2004 2 SA 216 (SCA).

various ethical concerns which relate to prospective refusal of medical treatment. There are also practical problems with the enforcement of advance directives. These issues are discussed in more detail in the follow-up article.