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ENHANCING THE DOCTOR-PATIENT RELATIONSHIP: LIVING, DYING AND USE OF THE LIVING WILL

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A research report submitted to the Faculty
of Health Sciences, University of the Witwatersrand,
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Steve Biko Centre for Bioethics

JOHANNESBURG, 2008.

"And come he slow, or come he fast,

It is but Death who comes at last."

Sir Walter Scott

Declaration

I, Harriet Etheredge, declare that this research report - entitled "Enhancing the Doctor-Patient Relationship: Living, Dying and Use of the Living Will" – is my own unaided work, except where I have explicitly indicated otherwise. I have followed the required conventions in referencing the thoughts and ideas of others. It is being submitted for the degree of MScMed (Bioethics and Health Law) to the University of the Witwatersrand, Johannesburg. It has not been submitted before, for any degree or examination, at this or any other University.

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28 September, 2008.

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TO WHOM IT MAY CONCERN

Waiver:	This certifies that the following research does not require clearance from the Human Research Ethics Committee (Medical)
Investigator:	Harriet ETHEREDGE
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Project title:	Enhancing the doctor-patient relationship: living, dying and use of the living will
Reason:	The research for this project is a review of published literature in the public domain. No human participants will be studied.

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Abstract

The research aims to establish whether processes around the consideration and execution of the living will help enhance the doctor-patient relationship. Studies have shown that the living will is not used frequently, and that the doctor-patient relationship is often deficient. The research explores the two primary topics – the living will, and the doctor-patient relationship – separately. Each primary topic is approached via a consideration of the relevant literature, and each is then analyzed from a theoretical–ethical point of view. A synthesis of these separate investigations is presented. This synthesis concludes that the living will can help enhance the doctor-patient relationship.

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Chapter 1: Introduction

This chapter will briefly provide introductory details concerning my research report. Section 1.1 will provide a brief summary of the research question and an outline of the topics into which this research will delve. Section 1.2 will detail the specific objectives for this research. Section 1.3 will explain the structure of the arguments in this research and the manner in which they are presented.

1.1. Introductory Summary

This research aims to determine whether the living will could be used to facilitate delicate and often difficult discussions regarding end-of-life treatment, and death, between patients and their doctors. Recent studies, appraisals of which will constitute a large component of Chapters 2, 3 and 4, have shown that, for the most part, both patients – especially those over 65 and those with a terminal disease - and doctors believe that discussing end-of-life care and dying would be beneficial in the continuous quest to improve patient care.

Such discussions would in particular further the ends of patient autonomy, beneficence and informed consent which have become ethical issues at the forefront of medical practice. In spite of these potential benefits, many patients remain unwilling to discuss death with their doctor. At the same time, many doctors remain unwilling to discuss death and end-of-life care with their patients. This could be because the idea of death, and discussions about it, are 'taboo'. Often it is also a psychologically uncomfortable area for both doctors and their patients.

As a possible solution to the above concerns, this research aims to determine whether the introduction of the subject of the living will – either by the doctor or by the patient – could, through the ensuing discussions, help facilitate a better doctor-patient relationship. The living will is a document referring specifically to end-of-life care and death. May it be considered a stratagem for enhancing patient autonomy, patient privacy at the end of life, and for allowing individuals some manner of control over their death in the event of incompetence?

1.2. Objectives

The overall objective of this research is to determine whether the living will could be used as a means to initiate and facilitate delicate discussions regarding end-of-life care and planning for death.

The specific objectives of my research are as follows:

A. To evaluate the perceived value of the living will to both patients and medical personnel.

B. To establish whether regular doctor-patient communication could ensure that the level of informed consent remains ethically acceptable

C. To evaluate the perceived importance of the doctor-patient relationship according to patients and medical personnel.

D. To discuss some barriers towards end-of-life discussions, and the unwillingness, on the part of both doctors and patients, to talk about death.

E. To briefly propose a system by which living wills may become more commonplace and hence may serve to facilitate end-of-life discussions and enhance the doctor-patient relationship.

These will be dealt with throughout this research report. Discussions and conclusions regarding these specific objectives will enhance the overall argument of this thesis.

1.3. Presentation of Arguments

This research report takes the form of three chapters (2, 3 and 4) concerning the body of the research and the main research question. The conclusions are presented in Chapter 5.

Chapter 2 has as its subject the living will. It presents a background to current thinking regarding this concept and it explores some of the frequently voiced pros and cons. This chapter contains findings relevant to specific objectives A and B. It will conclude with an ethical analysis.

Chapter 3 focuses on the doctor-patient relationship. Its structure follows that of Chapter 2. It concerns specific objectives C and D. It also concludes with an ethical analysis.

Chapter 4 is a synthesis of findings from Chapters 2 and 3. This synthesis helps provide an affirmative answer to the overall research question of whether the living will could enhance the doctor-patient relationship.

Chapter 2: The Living Will

2.1. Introduction

In this chapter, I will consider the living will and advance directive in more detail.[1] I will begin with a literature review in section 2.2. This review will consider articles published predominantly in established medical journals and bioethics textbooks. I will explore literature both for and against living wills from a practical and ethical point of view. Following this, I will consider the first two specific objectives of this research in Sections 2.3 and 2.4 respectively:

A. To evaluate the perceived value of the living will to both patients and medical personnel.

B. To establish whether regular doctor-patient communication could ensure that the level of informed consent remains ethically acceptable.

In Section 2.5 I will present an ethical analysis of the concept of a living will, arguing that it furthers the ends of ethical medical practice, and hence should be encouraged.

2.2. Literature Review

2.2.1. The Practicalities of the Living Will

[1] I will use the terms living will and advance directive interchangeably from this point forward as they refer to the same thing.

In his article entitled *Sharing Death and Dying: Advance Directives, Autonomy and the Family* Mun Chan (2004: 88), offers some insight into what exactly constitutes a living will and its uses. He begins by noting that the concept of an advance directive is a liberal one and claims that it has arisen in response to medical practice which was considered over-paternalistic. He then distinguishes between two types of advance directive. The first is an 'instructional directive' which "states a competent patient's instructions for healthcare when she lapses into incompetency" (ibid: 89). The second is a 'proxy directive' which "appoints another person to make healthcare decisions on the patient's behalf when she loses the ability to decide for herself" (ibid: 90).

The concept of the 'instructional directive' is essentially simple, though it can run into problems which are, however, beyond the scope of this research. The instructional directive specifies one's preferences for treatment by means of a written set of medical instructions. This is then signed and dated. It takes precedence over a familial proxy, though is thought to be most effective if used in conjunction with a familial proxy.

Mun Chan then considers the proper role of the proxy when it comes to the proxy directive. In order to make a properly informed decision the proxy should "consider the personality, moral values and religious beliefs of the incompetent patient in order to try and understand what she would have decided if she had known, while being competent, that she would be in the situation facing the surrogate decision maker" (ibid: 90 – 91).

Closer to home, *The Living Will Society of South Africa* more closely restricts the concept of the living will by noting that its main function is to aid in the "refusal of artificial life-support when

dying" (Living Will Society 2008). This society provides a framework for the creation of a living will as well as the support necessary to have the will carried out in the appropriate manner.

The vast majority of literature regarding living wills stresses that the concept is still imperfect and that much needs to be done to refine it and make it more effective. Some of the practical problems with living wills, as debated in the literature, will now be discussed.

In their article *Living Wills and DNR: is Patient Safety Compromised?* Mirarchi and Conti (2007: 66) point out that living wills are not individualized and that they are often open to misinterpretation. Often, it is claimed, they lack individualization as they are created using a template which may not incorporate the specific and specialized needs of each patient (ibid: 66). Furthermore, they "may not express the patients' true wishes" and the living will is often automatically interpreted as a DNR [Do Not Resuscitate] order" (ibid). The justification for the claim that the living will may not represent a patient's true wishes is that living wills are often left on file for years. The patient tends not to update it, thereby not incorporating any changes in personal opinion, nor advances in medical technology (ibid: 67). In his scathing criticism concerning living wills, Tonelli notes that another problematic aspect of living wills is that they are often unavailable in an emergency or are "not applicable in many situations involving critically ill patients" (Tonelli 1996: 816).

Although a substantial portion of the literature review has shown that the living will is often criticized, other literature suggests that it can be of great use if properly implemented and maintained. Kuhse and Singer (2006: 262 – 263) explore reasons why the living will has become desirable. Firstly, even though medicine is continually increasing its capacity to prolong life, this has not been matched by its ability to restore function and wellbeing (ibid: 262).

Secondly, for many today, the period before death is one characterised by a certain amount of mental incapacity. Given this state of affairs, the living will presents an attractive option, allowing a previously competent person to direct his or her medical treatment when he or she lapses into incompetency (ibid).

2.2.2. A Practical Example

An example of how a living will might have been beneficial, and saved many people a great amount of stress and grief, can be demonstrated by applying it to the Nancy Cruzan case.

On January 11th 1983, 24 year-old Cruzan lost control of her car on an isolated stretch of road in Missouri, USA. Although paramedics on the scene managed to restart Nancy's heart, her brain had been anoxic for fifteen minutes and she did not regain consciousness (Pence 2008: 28). Nancy remained in a persistent vegetative state (PVS) for 7 years following her accident. As the years went by, her body became rigid, her fingernails claw-like and her hands tightly clenched. She had to be rotated in her bed every two hours in order to prevent bed sores. She drooled continuously, leaving her hair and pillows wet and clammy (ibid). Furthermore, Nancy could not swallow and thus she had to be fed by a tube inserted into her stomach (ibid: 29).

Nancy's parents believed that she would not have wanted to exist in such a state. Thus, they sought permission in court to disconnect Nancy's feeding tube and allow nature to take its course (ibid). The Missouri Supreme Court ruled against the Cruzans, stating that, in the absence of an explicit advance directive authored by Nancy, they had not produced "clear and convincing" evidence that she would not have wished to exist in such a state (ibid).

Important here is the ruling of the court. It is apparent that this ruling would have been very different had Nancy made a living will. Should she have done so, she would not have been kept

alive in a manner she may well have deemed unacceptable and demeaning. She would also have been able to express her explicit wishes as to her treatment should the time arise that she became mentally incapacitated. Instead, due to the absence of a living will, a string of court appearances and appeals led to Nancy being kept alive for a far lengthier period than would have been the case had she made a living will. Eventually, in mid-1990, after a relentless, emotionally draining legal battle, intensely scrutinized by the media, the Cruzans won permission to disconnect Nancy's feeding tube. She died on December 14th, 1990 (ibid: 31).

The case of Nancy Cruzan also illustrates another, perhaps more cynical, way in which a living will could have been beneficial, not to Nancy, but to the general public. During her seven years in a PVS, Cruzan's care cost the State of Missouri US$ 130 000 per year (ibid: 28). Thus, the total cost of Nancy's hospitalization was US$ 910 000. Had she written a living will, and her life not been unreasonably prolonged, the State would have saved the state a vast sum of money. This saving could have been channeled elsewhere, perhaps to somebody who would truly benefit from the medical care such money promised. It may seem to many somewhat harsh to apply a financial analysis to Cruzan's tragic case. However, scarcity of resources is a medical reality worldwide and it should not be overlooked. From this societal point of view, a living will may be beneficial, by helping to channel medical resources away from patients who do not wish to use them, especially at a cost to others.

2.2.3. Ethics and the Living Will

Many ethical concepts are at play when it comes to living wills. Among these are:

- Autonomy,
- Informed consent,

- Beneficence.

Discussion of the living will also tends to open up the euthanasia debate to some extent. In Section 2.2.3 of the literature review, I will consider the literature under these four categories.

2.2.3.1. Autonomy

The vast majority of literature regarding the living will emphasizes the concept of autonomy[2]. It will be explored in much greater detail in Section 3.4.2.

In *Pulling the Plug on Living Wills* (see Section 2.2.1. above), Tonelli considers autonomy and its implications for the living will. He (1996: 816) begins by claiming that "the recent emphasis placed on patient autonomy within medical ethics has had a profound influence not only on the practice of medicine, but on the concept of autonomy itself". Indeed, he argues that autonomy has become "so integral to medical decision making that it is advocated as a guiding principle even in individuals who are no longer autonomous" (ibid). He goes on to suggest that the advance directive has come about in response to the assertion that "the right of self-determination is not lost in incompetent, and therefore non-autonomous, patients" (ibid).

2.2.3.2. Informed Consent

[2] Autonomy is the ability to be self-determining. An agent can only be truly autonomous if he or she is familiar with all the intricacies of his or her situation. In medicine, autonomy is preserved by means of informed consent, defined in Footnote 3 below.

Mirarchi and Conti focus on the issue of informed consent.[3] Notwithstanding the claims made by the *Living Will Society* (see Section 2.2.1. above), Mirarchi and Conti (2007: 67) claim that "Living wills lack the process of informed consent". This is because when a patient makes a living will he or she is often not made aware of all possibilities that may be available. The information regarding possible life-ending and life-sustaining treatments as it is provided by doctors is often generic and may not be discussed in sufficient detail to allow a living will to be signed with fully informed consent (ibid).

2.2.3.3. Beneficence

Tonelli (1996) also discusses the principle of beneficence. The ethical intricacies of this principle are explored in more detail in Section 3.4.3. He argues that the notion of the beneficent, paternalistic doctor – one who always acts in the best interests of his patient - should not fall by the wayside.

In order to make his point he uses the example of a once famous mathematician who now has dementia. He notes that this patient is always smiling, seems contented with his lot and when questioned about his contentment replies in the affirmative. This is the case in spite of the fact that when the mathematician was lucid he "held [his] cognitive powers in the highest regard" (ibid: 817). These powers were held in such high regard, in fact, that the mathematician had made a living will stating "quite unequivocally and even in writing, that he would prefer not to exist rather than live without them" (ibid). Tonelli (ibid) then goes on to claim that it is

[3] Informed consent entails that a patient has thorough knowledge of the nature and extent of risk concurrent with a medical procedure. Furthermore, the patient must show appreciation and understanding of the risks and benefits of a procedure. The patient is then in a position to make an informed consent to the entire medical procedure, including its consequences (McQuoid-Mason 2008: Handout).

reasonable to assert that this mathematician is not the person he used to be and thus not the same person who wrote the living will.

The ethical dilemma here concerns, on the one hand, respect for the autonomy of the mathematician versus, on the other, paternalistic beneficence which recognises that this mathematician is happy in his present state (indeed he does not even remember the previous extent of his cognitive powers).

Simonds (2003) considers beneficence from a different perspective. He claims that a beneficent doctor has a duty to "do all he can to palliate symptoms and maintain or even prolong a quality of life that is acceptable to the individual" (ibid: 276). A patient's living will dictates what he or she considers an acceptable quality of life.[4] A beneficent doctor then, is one who adheres to the wishes expressed in the living will.

2.2.3.4. Euthanasia

Here the euthanasia debate comes into play.[5] The case of the mathematician mentioned above is one that would demand an act of active euthanasia on the part of the doctor in order to fulfill the request of the living will. This is still beyond the compass of the law in most countries and it

[4] The "Quality of Life" debate has become a central issue in Bioethics. The two primary positions are as follows: There is the more liberal position which advocates that nobody should have to live a life which they judge to be of an unacceptable quality. For instance, an Olympic athlete may consider life as a quadriplegic after a car accident of unacceptable quality. Then there is the more conservative, religious position. This position stresses that God gave us our lives and he determined the route they would take. This faction advocates against a subjective judgement regarding quality of life, claiming rather that this judgment is up to God.

[5] There are three categories of euthanasia and each category has it own unique, distinguishing properties. The first distinction is between Active and Passive euthanasia. Active euthanasia entails using an active means to bring about death, for instance a lethal injection. Passive euthanasia occurs when a person refuses to intervene in order to prevent death, for instance the decision not to ventilate a patient. The second distinction is between Assisted and Unassisted euthanasia. Assisted euthanasia occurs when one requires the assistance of an outsider to die. Unassisted euthanasia involves taking one's own life and is thought of as suicide. The third distinction is between Voluntary, Involuntary and Non-voluntary euthanasia. Voluntary euthanasia occurs when a person explicitly agrees to the procedure. Involuntary euthanasia takes place against the explicit wishes of the agent and is considered murder. Non-voluntary euthanasia occurs when the subject is not positioned to gauge the situation, for instance an infant who is allowed to die due to illness (Van Bogaert 2007 (a): 750 – 753).

highlights an important problem with living wills: the requests they make of doctors often extend beyond what is permitted within the scope of the law. In some cases euthanasia is also unethical, but this debate is beyond the scope of this research.

2.3 Specific Objective A: The Living Will, Healthcare Professionals and Patients

This section deals with the specific objective of establishing the perceived value of the living will to medical personnel and patients.

2.3.1. The Living Will and its Perceived Importance to Healthcare Professionals

A study conducted amongst geriatrician members of the British Geriatrics Society regarding the living will yielded some interesting results. In the study entitled *Living Wills and the Mental Capacity Act*, Schiff *et. al*. (2006: 116) found that many of the geriatricians practicing in Britain had experience with the living will. Most of this had been positive and many geriatricians felt that the living will was useful (ibid: 118). The main reasons for this sentiment were the following:

- The living will was seen as a tool which allowed doctors to easily carry out patients' wishes for "less invasive, predominantly palliative care at the end-of-life" (ibid).
- The living will meant that those who had requested to die at home were much more likely to actually do so (ibid).

In spite of the positive response to the living will, studies show that many healthcare professionals are themselves unwilling to actually sign such a document. A study by Go *et. al.* (2007) looked into *Advance Directives Amongst Healthcare Professionals at a Community*

Based Cancer Centre. In spite of the fact that the 134 study participants worked closely with terminally ill patients, it emerged that only 35% had actually executed advance directives for themselves (ibid: 1487). The study found, however, that this was due to a lack of easily accessible documentation rather than to the fact that the participants did not believe the living will to be potentially valuable. Of those who had not executed an advance directive, most in this study said they intended to do so.

2.3.2. The Living Will and its Perceived Importance to Patients

Studies considered in this section reveal that, like healthcare professionals, patients usually feel that a living will could be of great importance when it comes to the direction of their future medical care.

For example, Simonds (2003: 276) found that the presence of a living will "provides many individuals with comfort and reassurance that the care they receive will be in accordance with their wishes." He also noted that a recent survey of elderly people living in London found that, once informed of the possibility of a living will, 74% expressed a desire for their own (ibid: 278). This finding suggests that knowledge about living wills is scarce amongst patients. The means to make a living will - in the form of easily accessible documentation - also seems limited amongst patients, as it is amongst doctors.

Although there are some problems with living wills, practicing medicine in an ethical fashion must always be prioritized. It is clear from the literature reviewed that patients are enthusiastic

about the living will. Restricting its use, then, is failure to recognize a patient's autonomous choice, should he or she wish to make a living will. Similarly, restricting the use of the living will is not beneficent in the case of a patient who is keen to make one. Given the positive attitude of patients towards the living will, it appears that medical practitioners should aim to promote and implement them widely.

2.4. Specific Objective B: The Living Will, Ethics and Informed Consent

This section deals with specific objective B: establishing whether regular doctor-patient communication could ensure that the level of informed consent remains ethically acceptable.

Since medical advances in the future cannot be predicted with certainty, consent in a living will can never really be "fully" informed. However, it appears that good doctor-patient communication regarding the living will can make any consent as fully informed as possible.

2.4.1. Why the Emphasis on Informed Consent?

Many of the specific problems relating to the living will concern the uncertainty inherent within them. Pence (2006: 49) sums up the two most prominent concerns:

- It has been found that most people do not accurately predict their sentiments towards extraordinary medical treatment when they are actually near death. Sentiments change over time and often those who presently claim to dislike the idea of being kept alive at all costs change their minds as they near dying.

- Studies have shown that those designated as legal proxies cannot ascertain the wishes of previously competent, but now incompetent, individuals with any measure of accuracy.[6]

[6] Pence does not explicitly address the issue of how to ascertain whether proxies are accurate or inaccurate. This would require some kind of response from the patient, by definition incompetent in these situations. It is possible

Both of these points relate to informed consent. As medical technology advances, it is important that a living will-maker consents to, or refuses, new treatments. Then any change in sentiment will be well informed by knowledge of the treatment available. Proxy decision makers, who will make decisions for the patient upon his or her incompetence, are giving an informed consent on behalf of the patient. For this consent to be as informed as possible, it is important that the proxy is familiar with the patient's sentiments and changes therein.

2.4.2. A Possible Solution

These important points suggest that those who make a living will should not do so lightly. They must be made aware that their sentiments may change, and that they must review the living will at regular intervals. They must also be sure to continually inform their designated proxies concerning their wishes in the case of incompetence. This should constitute a component of a frequent review process. The patient must be made aware of the benefits of this, as well as the dangers of infrequent reviews.

This regular review depends upon good communication. It is very important that the patient discuss his or her wishes with both doctor and designated proxies. The role of the doctor should be to facilitate the review of the living will, and to help encourage his or her patient to keep it up to date. Time should be taken to explain advances in medical technology to the patient. Changes in sentiment on the part of the patient should also be evaluated and the living will

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that studies regarding the correlation between proxy decisions and the patient's actual wishes could be conducted using the patient's living will as a guideline. However this is problematic, as a proxy should always be familiar with the relevant living will.

updated accordingly. This information should then be disseminated amongst proxies by the patient, ideally both verbally and in writing.

By its conventional definition, informed consent is 'consent to medical treatment after such a time as the patient has been made well aware of the potential risks and benefits of the treatment'. The informed consent process is a fluid one, and it changes along with sentiment as well as technological advances in medicine. Informed consent is possible here via consent to, or refusal of, certain forms of medical treatment; and by consent to conscientiously re-evaluate the contents of the living will. If a living will represents consent to future medical treatment - and because medical advances are frequent - then for this consent to be informed, it is vitally important that the document is kept up to date and that proxies are kept well-versed in its contents.

Provided the living will is kept up to date, and regularly discussed with a doctor who will explain the risks and benefits of new medical advances; it would appear that the process of consent to, and / or refusal of, future medical treatments, as stipulated in the living will, is as ethically justifiable as it can be. Nobody can predict the future with certainty, but keeping a living will current minimizes the chance that when it comes into effect it does not properly express the autonomous choice of the person who made it.

Thus it appears here that discussing the living will with one's doctor and designated proxies could yield a more ethically sound living will. This living will would be more ethically relevant because, when handled as a topic to be discussed with doctor and proxies (who are often family members or close friends) ethical ideals are specifically and individually considered. These ideals include a consent which is as 'fully informed' as possible, given that we are dealing with prospective medical treatments. Also included is beneficence, in which the doctor undertakes to

preserve the quality of life, considered acceptable to the patient, as stipulated in his or her living will.

These ideals of informed consent and beneficence may be reinforced by discussions in which all aspects related to the living will are addressed by the role players: the patient, the doctor, and proxies. An ethical living will is one made in the light of as many ethical ideals as possible. This is clearly a result of these ideals being furthered by means of doctor-patient discussions and finds its place in the element of trust which is central to the doctor-patient relationship. If properly implemented, the use of the living will could lead to increased confidence amongst both patients and the medical profession, as it goes some way towards allaying the doubts regarding patient sentiment expressed in Section 2.4.1.

2.5. Ethical Analysis

Having considered the literature pertaining specifically to the living will, and the way in which detailed discussions can yield a more ethically acceptable living will for all who wish to make one, I will now consider the living will as a whole, and ask: "Is it ethical?" This ethical analysis of the living will hinges upon two prominent ethical theories, Kantianism and Utilitarianism, each of which will be discussed in turn.

2.5.1. Is the Living Will Ethical? – Kantianism

2.5.1.1. Introduction

Kant (1724 – 1804) lived during the Enlightenment and developed his theory of ethics with the firm belief that the power of reason is sufficient to solve all human problems (Pence 2008: 162). Kant's Deontology was based on duty and the idea that the consequences of an action were of

little import in comparison to the *reason* for that action (ibid). Kant encouraged people to do their duty: to do what is right and display a "pure will" (ibid). The first and second formulations of Kant's Categorical Imperative are of great importance to Bioethics and provide a useful guide when it comes to medical decision making.

The first formulation of Kant's Categorical Imperative states:

> *Act only in accordance with that maxim through which you can, at the same time, will that it become a universal law* (Gregor 1997: xviii).

My understanding of this first formulation is as follows: It is like saying 'treat others as you would be treated by them', but in a broader sense. If the maxim of your action were to become a universal law, then you too would be subject to such actions. So if you acted towards somebody else based on a malicious maxim, should your malicious maxim become a universal law, you will then also be treated with malice.

An example of the first formulation of the Categorical Imperative is as follows: Assume Marty wants to donate his worldly savings to charity, preferring a life of quiet contemplation. The maxim of his action here is: 'it is good to act in such a way that one donate one's worldly savings to charity'. Should this maxim be a universal law, everyone would be required to donate all their worldly savings to charity. Categorical Imperatives are absolutes and there is no opt-out clause. So the charities would have all the money and the people would have nothing. This example shows that Marty's action of donating all his worldly savings to charity is not a good one as the maxim of his action cannot be construed as a universal law without giving rise to a ridiculous situation.

When it comes to medicine, the first formulation of the Categorical Imperative advocates that a doctor should treat patients in a manner which he or she would like all other doctors to employ, and would be happy to experience as a patient him or her self.

The second formulation of the Categorical Imperative, which has also become very important to medical ethics, states:

> *So act that you use humanity, whether in your own person or in the person of any other, always at the same time as an end, never merely as a means* (Gregor 1997: 38).

The second formulation may be paraphrased as: 'always treat others with respect as autonomous human beings and never as mere instruments'. This means that we may not use other people merely as instruments towards fulfilling our own goals. This is not to say that one cannot use another as a means to fulfilling an end. It is important however that the autonomy of the other is preserved.

When it comes to medicine, this can be construed in light of informed consent and informed refusal. The second formulation advocates that doctors, for instance, should not perform personal research experiments on their patients without their informed consent. It is not wrong for the doctor to use patients in his or her research, but it is wrong to use patients *merely* for this, especially without consent.

An example from Nazi Germany illustrates the second formulation in a practical manner. Dr Josef Mengele was particularly interested in the genetic structure of the blonde haired, blue eyed 'Aryan' race. These features were considered to epitomize the ideal human under Hitler's regime. Mengele believed that twins held the genetic secrets of the Aryan race and he was under

the impression that if an Aryan woman could assuredly give birth to blonde haired, blue eyed twins, the future could be saved (Rosenberg 2008: 1). Given these beliefs and the purpose of Mengele's research, an ideal area of operation was one where there was no shortage of twins who could be used as specimens (ibid). Thus Mengele entered Auschwitz concentration camp as an experienced medical researcher in May 1943. His experiments were funded by the German government and he worked alongside some of the top medical researchers of that era (ibid).

The twins selected for genetic experiments at Auschwitz became known as "Mengele's Children". During the course of his research Mengele carried out experiments on approximately three thousand twins. Only two hundred of them survived (ibid). The experiments were brutal in nature: "Blood, often in large quantities, was drawn from twins' fingers and arms, and sometimes both of their arms simultaneously. The youngest children, whose arms and hands were very small, suffered the most: Blood was drawn from their necks, a painful and frightening procedure" (ibid: 2). Additional experiments included the instillation of drops or injections of chemicals into twins eyes in an attempt to fabricate a blue eye colour. These were painful procedures, often resulting in blindness. Surgery was performed on some twins without anesthesia. These twins usually died after the third or fourth surgery, following which the final experiment, an autopsy, would be performed (ibid).

It is easy to apply the second formulation of the Categorical Imperative to the example of "Mengele's Children". Although they were children and as such may not have explicitly formulated their own ends and what exactly these might be, I believe it is safe to generalize some ends these children might have desired. As is the ultimate end of most people, I think it is safe to say that the desired ends of these children would have included health and happiness, or something similar. Mengele's end was the acquisition of genetic and medical information in

order to further his research into Aryan genetics. "Mengele's Children", as their name suggests, were used solely as a means to Mengele's end of furthering genetic knowledge. There was neither informed consent nor any respect for these children as intrinsically valuable human beings. Mengele's use of these children towards his own ends is a direct violation of the second formulation of the Categorical Imperative and thus his actions were morally reprehensible.

2.5.1.2. Categorical Imperatives and the Living Will

This section aims specifically to establish whether the concept of a living will is ethically sound, according to the first and second formulations of Kant's Categorical Imperative.

The living will is a document which specifies medically related actions to be taken at a stage in a person's future when he or she cannot express his or her explicit wishes for medical treatment independently. A person generally makes a living will under the premise that the preferences for medical treatment expressed therein will be carried out and respected at such a time as the living will takes effect. Thus implementing requests expressed in the living will, when the time arrives, is constructed on the maxim that honoring such requests is the best thing to do as this is what the patient expected upon writing the will.

The first formulation of the Categorical Imperative states that an action is morally acceptable if the maxim of that action can be generalized into a universal law, one to which all people will be subjected. It is ethical, then, to implement requests in a living will when the time arrives to do so. This is because, when such instructions are heeded, doctors are acting on the maxim that people make a living will fully expecting it to be respected. This maxim is easily universalisable. No one would write a living will if it were just to be ignored. Here it is evident

that carrying out the wishes expressed in a living will is morally permissible according to the first formulation of the Categorical Imperative.

As considered in the literature review, the living will is also an instrument used in preserving patient autonomy upon the event of incapacity. The living will speaks for the patient, dictating that patient's wishes for his or her medical treatment. The second formulation of the Categorical Imperative, that people should always be treated as ends in themselves, is easily applicable here:

> P1) Within the framework of morality, the living will expresses autonomous peoples' individual requests and wishes.
>
> P2) According to the second formulation of Kant's Categorical imperative, it is morally right only to treat people as ends in themselves, not merely as a means to some other end.
>
> P3) Treating people as 'ends in themselves' implies, *inter alia*, complying with their requests and wishes as long as they are within the framework of morality.
>
> C) Therefore acting on requests stated in the living will, and complying with people's wishes within the framework of morality, is ethically correct according to the second formulation of the Categorical Imperative.

This analysis of the living will shows that the concept meets ethical tests in two important areas. Firstly the application of the first formulation to the concept shows that the maxim upon which a living will is made, and upon which it is carried out, is universalisable. Secondly, application of the second formulation shows that the living will is morally defensible as it treats people as ends in themselves, respecting their intrinsic dignity and worth.

2.5.1.3. Categorical Imperatives and the Living Will: Objections

Certain objections to my conclusion that the living will is an ethically acceptable concept according to Kant's Categorical Imperative could be voiced. I shall explore only one of them here[7].

For the sake of simplicity, I am going to use the example of a hypothetical person called Erica. Erica made a detailed, unambiguous living will when she was first diagnosed with Huntington's chorea. Fully aware that this disease would render her unable to communicate coherent treatment preferences as she neared death, Erica made the decision to let her living will speak for her.

In Section 2.2.3.3, Tonelli (1996) noted that the competent person who made a living will was not the same person as the incompetent person he or she has now become. He used an example of a brilliant mathematician. This suggests, in the present example, that the ends of the previously competent Erica have changed upon her lapse into incompetence. The living will made by the previously competent Erica has been voided by dint of her transition into incompetence. As two different people, it is likely that Erica has two different 'sets' of ends: A 'set' for the previously competent Erica which was expressed in her living will; and a second 'set' for the now incompetent Erica who, although she has this new 'set' of ends, cannot express them because she is incompetent and thus will not be taken seriously for any number of reasons.

It is evident that this objection results in a "Catch 22" situation for Erica and anyone else who has made a living will whilst still competent. It is like saying: "Sorry Erica, but whatever you said before, we'll ignore. Rather, we will do what we think is best for you." This is clearly treating Erica as a means, certainly not as an end in herself. For those who, for whatever reason,

[7] This is, in my opinion, one of the most frequently voiced and inhumane objections to the living will. I have chosen to discuss it in detail here rather than briefly considering the whole range of objections to my argument.

consider the living will to be integral to their future medical treatment this Catch 22 could be a frightening and intimidating moral problem – the last thing which one who is already seriously considering the circumstances of his or her death wishes to deal with.

The "Catch 22"[8] revolves around two 'facts':

1. The previously competent Erica's living will is not going to be taken seriously as the previously competent Erica is now incompetent (and therefore a totally different person to the previously competent Erica who made the living will!)

2. By virtue of this incompetence, Erica will still not be taken seriously at present. (This is because no one would seriously consider an incompetent person's expression of treatment preferences given that they are obviously incapable of making such decisions.)

Therefore, in short, if this objection is to hold any water, we would all have to agree that Erica's express wishes for treatment, as an incompetent, ought never to be taken seriously. Whether she was competent or incompetent when she expressed the wishes does not matter. This is because, according to this objection, previously competent Erica is not the same person who made the living will now that she is incompetent. This incompetent Erica is a different person. In fact, I would be justified in changing her name at this stage – lets call her Mary. The fact that Mary is incompetent means that she is in no mental state to express her wishes. After all, incompetent people are incapable of making rational decisions.

It is evident here that this objection, when really unpacked, verges on the ridiculous. It seems to be suggesting that Erica / Mary's wishes for treatment should be disregarded whether she is

[8] The original "Catch 22" appeared in Joseph Heller's novel of the same name. An air force pilot, who wishes to be taken off active duty, is obviously sane by virtue of this wish, and hence must continue. By the time he becomes insane, the wish has disappeared and his flights of duty therefore continue (Heller 1961).

competent or incompetent. Erica's wishes regarding the treatment of Mary cannot be taken seriously as the competent Erica, and Mary for whom she is making the directive, are not the same person. Mary cannot be taken seriously in the expression of her wishes as she should not be treated as a person at all and certainly not as an end. Because she is incompetent, Mary should be made to relinquish all control of her care as she has no idea what is good for her anyway.

In conclusion, advocates of this objection, like Tonelli (1996), run the risk of being seen as over-paternalistic and controlling. People like Erica / Mary are categorized into a medical 'box' which defines who they are and how they ought to be treated. They ought not to be treated according to their express wishes, they ought not to be treated as ends in themselves. It seems then that the only option is to leave it to chance. Those who have made a living will should hope that the doctor in charge of their compassionate care will consider the terms of their living will. The upshot of this objection is simple: No Living Wills!

There may yet be some hope for these hopeless cases, however. Ethical doctors are likely to remember that any maxim for action must be generalized as a universal law. I have shown that this is no trouble when it comes to living wills and that they are morally justifiable in this sense. Most doctors are also moral in this sense.

2.5.2. Is the Living Will Ethically Acceptable? – Utilitarianism

2.5.2.1. Introduction

Utilitarianism was developed principally by Jeremy Bentham and John Stuart Mill in the late 18th and early 19th century (Pence 2008: 164). It came about as a response to puritanical Christian ethics which advocated that everyone obey the rules of Christianity (ibid).

The essential idea of Utilitarianism is a simple one: "Right acts produce the greatest amount of good for the greatest number of beings" (ibid). This 'good' is called 'utility' (ibid). This means that actions should be judged according to their consequences, not the motives and intentions for doing them. If an action benefits more people than those it harms then the action is acceptable from a Utilitarian point of view.

When it comes to medicine, a good example of Utilitarianism in practice can be gleaned from *Pernkopf's Topographical Anatomy of the Human Being*. This book has become a "classic of anatomical literature" and it is valued for its detailed illustrations (Knapp Van Bogaert 2008: Handout). It is possible, however, that the bodies of some Second World War concentration camp victims were used as models for the illustrations.

From a Utilitarian point of view, these actions against the prisoners of war can be found morally acceptable. This is because only a small number of people suffered harm in the compilation of the anatomy textbook.[9] On the other hand the publication of the book has benefitted many and in some cases, continues to do so. It has benefitted medical students and doctors who, in turn, have used knowledge gained from the book to benefit their patients.

So the final tally is that many more people have benefitted from the actions taken by Pernkopf and his team than the small number of Jews who were harmed in the compilation of the book. In Utilitarianism the consequences of an action are of import. The action itself, and whatever morally reprehensible activities it involves, can be morally justified if benefits outweigh harm.

[9] Even though about six million Jews lost their lives in the Second World War, only a tiny fraction of this number were killed and then used as anatomical, cadaverous models for the textbook.

This is the case with Pernkopf's book. According to Utilitarianism, then, this book is not ethically suspect.[10]

2.5.2.2. Utilitarianism and the Living Will

This section aims to establish whether the concept of a living will is an ethically justifiable one according to Utilitarianism. Unlike the Kantian analysis presented above, Utilitarian analysis is not as 'cut-and-dried'.

For the purpose of argument, here I assume that Sando has made a living will, and that there is no question that his wishes stated therein will be respected. Sando will die in the manner he has specified and with the dignity he desires. The action of writing the living will has, then, most certainly benefitted Sando. It has given him emotional and physical security in the years of his life since he wrote the will. The fact that his death will be acceptable to him could be considered a posthumous benefit to Sando also.

Sando, however, is just one person. Needing also to be taken into account here is the fact that "no man is an island entire unto himself" as John Donne famously wrote (The Oxford Dictionary of Quotations 1979: 190). This means that Sando's actions and decisions regarding his life influence the lives of other people. Although the circumstances of Sando's death will benefit Sando, it is possible that the total amount of utility will actually decrease as the result of Sando's living will. Those close to him who are aware of his decision may be distressed and unhappy about the situation as it becomes known to them. When the time comes for Sando's living will to take effect these people may believe that his death is premature and unnecessary at this time.

[10] The Utilitarian stand can be taken a step further here. If a greater amount of utility is required to render an action morally acceptable, it would make sense to continue use of Pernkopf's Topographical Anatomy today. This is because, as more people benefit from its teachings, utility increases. Therefore the action becomes more morally acceptable with continued use of the book.

In this example, then, the living will cannot be considered morally justified as there is an overall decrease in utility.

The reason why many people make living wills, and let us assume that this is also Sando's motivation, is that there is, *inter alia*, a wish not to be a burden. Sando made his living will not only to ensure for himself a dignified death, but also to ensure that the physical, emotional and financial wellbeing of his loved ones was preserved.

Assume Sando has motor neurone disease which will slowly take its toll on his life. He will eventually need full time care. This will either have to be paid for, representing a drain on finances; or it will have to be provided by a family member or friend. This person may well have to quit their job, losing out on the possibility of a steady income and secure retirement.

These factors may cause the caretaker great emotional, as well as financial, strain. Sando's family members may well be emotionally pained by his slow and painful deterioration. There may also be a certain amount of materialistic bitterness as Sando's medical care uses up resources which would have formed part of an inheritance.

Seen from this point of view, Sando's living will, effectively shortening the length of his illness, seems to provide an overall increase in utility. Sando will get the dignified death he desires, freeing him from unbearable suffering. Family resources will be preserved and Sando's death will not be greeted with bitterness. Here, there is only an increase in overall utility and thus Sando's living will can be considered morally justified from a Utilitarian point of view.

This analysis of the living will has shown that Utilitarianism does not shed much light on the ethics of the living will. This is dependent upon the stance which one takes and assumptions made concerning the reactions of affected individuals. From a narrow, even selfish, point of

view, utility could be said to decrease and therefore the concept to be unjustified. From a broader point of view, where the utility of all those effected is considered, according not only to their emotional wellbeing but also physical and financial utility, the concept seems ethically sound. The main point to be drawn from this ethical analysis is that Utilitarianism does not provide a definitive answer regarding the ethical status of the living will.

2.5.2.3. Utilitarianism: An Objection

The first section of my ethical analysis according to Utilitarianism dealt with the fact that the living will may be unethical as it may take an unnecessary emotional toll on Sando's loved ones. This would decrease their utility more than Sando's would increase as a result of his a living will.

One objection to this claim is that there would be a certain amount of emotional trauma whether Sando made a living will or not. The time will come when Sando is in great pain. Seeing him in such pain is likely to be emotionally harrowing for his loved ones. Eventually Sando will die and, as with all death, there will be a period of emotional hardship and mourning for his loved ones. This emotional state would come about whether or not a living will had been made. Thus, to say that the living will is unethical as it will force Sando's loved ones to contemplate his death, something which would be emotionally challenging, seems incorrect. Sando's loved ones would have to contemplate his death even in the absence of a living will.

Furthermore, the presence of a living will may make dealing with his death easier for Sando's loved ones. They will be familiar with his symptoms, with his wishes for treatment and there will be no ambiguity as to the medical care he would have desired. So, even though there will still be emotional difficulties it may be easier to come to terms with these as a result of the living will.

This limited emotional response may actually lead to an increase in the utility of all concerned, thus rendering the living will ethically defensible from a Utilitarian point of view.

2.6. Conclusion

In this chapter I have explored the living will. The literature reviewed has highlighted some of the pros and cons of the concept and has addressed some of the most frequently voiced concerns. I have also established two of my specific objectives, namely that A: both doctors and patients consider the living will an instrument of some importance, and that B: improved doctor-patient communication could facilitate a more ethically satisfactory living will based on consent which is as fully informed as possible. In my ethical analysis I have considered ethical arguments and prominent objections from a Kantian and Utilitarian perspective. I have replied to these objections.

Ultimately I have argued that the living will is ethically sound. It is of great importance to doctors and patients and if properly implemented and administered, it can be very valuable. As the living will is ethical, integrating it into medical practice should be a priority. It will serve to strengthen the doctor-patient relationship. Having established this, I can now move on to the doctor-patient relationship, which will be the subject of Chapter 3.

Chapter 3: The Doctor-Patient Relationship

3.1. Introduction

In Chapter 2 I looked at the living will and concluded that the concept embodies accepted ethical precepts and therefore it should be given sound consideration, as it is deemed important by both healthcare professionals and patients alike. In this chapter I will consider the concept of the doctor-patient relationship in more detail. I will begin with a literature review, considering the doctor-patient relationship under the headings of certain medical conditions and / or interventions. I have chosen to present the first section in this way as the living will pertains to end-of-life decisions relevant to medical conditions / interventions. My findings regarding the living will and the doctor-patient relationship will be synthesized according to some of the same medical conditions / interventions in Chapter 4.

Throughout Section 3.2 I will focus on specific objectives C and D. Objective C entails evaluating the perceived importance of the doctor-patient relationship according to patients and

medical personnel. Objective D involves identifying some barriers towards end-of-life discussions and addressing the unwillingness to talk about death. In Section 3.3 I will briefly summarize my findings regarding these two objectives.

Finally, I will present an ethical analysis of the concept of the doctor-patient relationship, arguing that it is furthered particularly by good doctor-patient communication. I will conclude that good doctor-patient relationships advance the ends of ethical medical practice and thus they should be encouraged.

3.2. The Doctor-Patient Relationship, Medical Conditions and Interventions

3.2.1. Introduction

For the purposes of this Chapter (and Chapter 4) the doctor-patient relationship can be defined as follows: A bond between doctor and patient which is strengthened by good communication and growing trust over a period of time. The relationship between a doctor and his or her patient can have beneficial treatment outcomes and, for the purposes of this research, can help that doctor understand and implement his or her patient's wishes.

Mun Chan (2004: 98) claims that "the dying process should be regarded as a sharing process, the last journey that the patient makes together with [his or] her significant others." These significant others include, most importantly, the patient's family and his or her doctor. The reason why these significant others should be kept aware of the patient's end-of-life wishes includes the idea that the patient is almost always a "connected / pluralistic" being (ibid: 95). As

such, the patient is defined according to relationships with others (ibid). As Aristotle asserts, we are social animals (McKeon 2001).

In order that those closely connected to the patient are able to contribute to this kind of 'emotional journey', it is imperative that they are kept informed of the patient's health status and prognosis. This is best achieved through good communication between all parties, thus strengthening relationships.

This communication should have the patient as the primary focus in order to preserve informed consent and autonomy. Epstein *et. al.* (2005: 415 – 416) note that the benefits of good patient-centered communication include the following:

- The patient feels understood upon inquiry into his or her needs, perspectives and expectations of quality of life and care.
- Attending to the psychosocial needs of the patient by involving family and loved ones gives the patient a feeling of security and belonging.
- One should encourage the patient's involvement in his illness by allowing him to make decisions about his health and the course of treatment to be followed. If this is done in conjunction with familiarizing the patient with the nature of his illness he will feel more in control of his circumstances.

Moreover Epstein *et. al.* (ibid: 416) note the if this type of communication is taken slowly, and with care on the part of the doctor, the patient will generally feel more confident about the doctor's abilities; and be more trusting of the doctor.

Given the beneficial consequences of a strong doctor-patent relationship, it is surprising that it is still neglected in some situations. Studies reveal that when it comes to joint decision making involving patient, family and doctor, communication is "inadequate" (Simonds 2003: 274 – 275). This lack of communication means that patients often do not receive the benefits detailed above.

A study by Pandhi and Saultz (2006: 394) found that interpersonal "continuity of care" enhanced the doctor-patient relationship. Interpersonal continuity of care is the idea that a patient is treated by the same doctor for a lengthy period of time This is because patients noted that, over time, doctors became more empathetic to their concerns. The patients also gained confidence to "express their needs" to their doctor (ibid). This review found that patients who experienced good continuity of care valued "active participation" with their doctor when it came to treatment discussions and decisions (ibid: 395). This active communication was valued especially highly by vulnerable groups such as the elderly, poor, undereducated and those with chronic conditions (ibid).

Pandhi and Saultz's study deals specifically with the elderly and those with chronic conditions, and it helps to determine whether the doctor-patient relationship is important to patients. Relating to specific objective C, this study suggests an affirmative answer to the question.

The notion that, as a pluralistic entity, it would be beneficial for a patient to make end-of-life decisions in conjunction with family and doctor, implies that family might be involved in sensitive discussions with the patient and his or her doctor. According to a study by Shields *et. al.* (2005:344) family members may be encouraged to accompany the patient to doctor visits, physical tests and examinations. A concern which is frequently voiced regarding accompanied visits to the doctor is that the presence of a family member or friend at the consultation may

detract the doctor's attention from the patient. Thus the patient's concerns are unlikely to be thoroughly discussed and addressed by the doctor (ibid).

In their study, which randomly allocated patients to attend visits accompanied or unaccompanied and then evaluated the quality of those consultation, Shields *et. al.* (ibid) found that the presence of a family member or friend did not result in less attention being paid to the patient's anxieties about, and preferences for, treatment. The findings of this study suggest that the worry voiced here is not necessarily of great consequence. It should not hinder family involvement in the final chapter of the life of a loved one.

Communication is fluid. The conversational style and technique required when entering into a conversation with patients and their families varies greatly given the nature of the illness as well as the emotional state of all those involved. It is becoming quite clear, however, that good communication skills help to build a good doctor-patient relationship. The remainder of Section 3.2 will explore studies relating to the doctor-patient relationship and relevant medical conditions.

3.2.2. Cardiopulmonary Resuscitation and the Doctor-Patient Relationship

A millennium study by Schiff *et. al.* (2000: 1641) found that 90% of their study participants, after the appropriate counseling and explanation of circumstances, would refuse cardiopulmonary resuscitation[11] at the end stage of a terminal disease. This would be achieved either by means of a direct request from the patient if mentally competent, or by means of a living will if incompetent or unable to communicate.

[11] Hereafter referred to as CPR

In a letter to the *British Medical Journal*, Wilks *et. al.* (2002)[12] made mention of the fact that, although talking about death and decisions for treatment may be very difficult, people generally value the opportunity to discuss CPR with their doctor. The group suggests that "sensitive preparation and good communication skills are required" and discussions based on these two often lead to "a beneficial effect on health outcomes" (ibid). Although discussions regarding CPR and the refusal thereof are complicated by the fact that no accurate prediction of outcome is possible, patients have been found to value the opportunity for expressing their preferences regarding CPR in future medical situations.

The conclusions of this study suggest that patients do value a good relationship with their doctor. This serves to provide support for my conclusions under specific objective C.

3.2.3. The Elderly and the Doctor-Patient Relationship

In their letter Wilks *et. al.* (ibid) observed that recent reports in the British media, and on television, suggested that it was cruel to discuss death with old people and that the whole topic of end-of-life should be avoided as people do not want to contemplate their death.

The study by Schiff *et. al.* (2000), mentioned above, records the views of some elderly people regarding doctor-patient communication, a relationship with their doctor and end-of-life planning. Contrary to the portrayal of the situation in the media, this study found that many elderly people have clear views on end-of-life issues and were forceful in their conviction regarding medical interventions at the end-of-life (ibid: 1641). It was found that elderly people

[12] Dr Michael Wilks – Chairman of the Medical Ethics Committee, British Medical Association, Mr Gordon Lishman – Director General, Age Concern England, Dr Bob Bingham – Chairman, Resuscitation Committee (UK) and Dr Beverly Malone – General Secretary, Royal College of Nursing.

wished that their views be known and were keen to discuss treatment plans with their doctors (ibid).

Schiff *et. al.'s* empirical research, entitled *Views of Elderly People on Living Wills: Interview Study*, supplements findings regarding specific objectives C and D. It appears that doctor-patient communication is important to the elderly and that it should be entered into on a regular basis. This study suggests that doctors should not consider the age of a patient as a barrier to talking about death. Elderly people value the opportunity to discuss treatment with their doctor and it is clear that age should not be considered a barrier to good doctor-patient communication. This would lead to an improved doctor-patient relationship.

3.2.4. Mechanical Ventilation and the Doctor-Patient Relationship

Simonds (2003) studied the impact of different forms of ventilation as they pertain to patients suffering with severe chronic obstructive pulmonary disease (ibid: 272).[13] This research notes that eventually, all those with this disease who express a wish for aggressive treatment, will progress to intubation and intermittent positive pressure ventilation (ibid: 273).[14] This is considered one of the most aggressive forms of respiratory treatment and a 59% mortality rate is reported in the year following commencement of IPPV (ibid).

[13] Hereafter referred to as COPD
[14] Hereafter referred to as IPPV

In a study by Pochard *et. al.* it was found that of a group of patients receiving IPPV, 88% were depressed, 58% felt unable to communicate, 37% experienced an acute fear of dying, 30% felt intolerable pain and 21% feared they had been abandoned (Simonds: ibid). It was also found that, following admission to ICU and IPPV treatment, 59% of survivors had a greater dependence on carers, worse exercise tolerance and a poorer quality of life (ibid).

Given this prognosis, it is not surprising that those with COPD express a desire to communicate with their doctor concerning the final stage of the disease, hospitalization and ventilation (ibid: 274). Many consider the prognosis with IPPV and the ensuing quality of life to be unacceptable, and they express a wish for palliative care at the end stage of the disease rather than invasive and painful ventilator treatment (ibid).

It becomes obvious that the doctor-patient relationship, and the close, interpersonal communication that comes with it, is very important in such circumstances. The patient must be made fully aware of the prognosis and consequences of IPPV and the doctor must also be aware of his or her patients' wishes regarding such treatment. Simonds (ibid: 274 - 275) notes that in spite of its beneficial consequences, doctor-patient communication regarding end stage lung disease is still lacking. It is noted that patients are not often familiarized with the burdens of aggressive treatment, despite guidelines and research evidence that this information does affect treatment decisions (ibid).

This section has very specifically detailed the poor prognoses of patients receiving IPPV. Hence discussions with medical personnel are very important as they help patients make better decisions regarding mechanical ventilation. This observation is relevant to specific objective C. Regarding specific objective D, it is noted that a clear barrier to communication in this instance

is the fact that whilst they are ventilated patients cannot talk. In order to promote an effective doctor-patient relationship, a doctor may be required to develop creative new methods of communicating with the patient whilst he or she is ventilated.

3.2.5. Dementia and the Doctor-Patient Relationship

Dementia represents one of the biggest challenges to the doctor-patient relationship.

In his article entitled *Advance Care Planning and the Relevance of a Palliative Care Approach in Dementia*, Hertogh (2006: 534) notes that family members of institutionalized dementia patients often experience a lack of important information. This concerns not only information relating to specific treatment decisions, but also that regarding the course of the disease (ibid). The progression from mild to moderate and then severe dementia is not easily defined. Often treatment of the condition depends more on intuition than evident pathology. This complication in discerning the stages of dementia, coupled with lack of information from doctors, makes it very difficult for family members to predict the prognosis for a loved one (ibid).

According to Hertogh (ibid: 555) the Netherlands is often considered to offer some of the most superior dementia palliative care in the world. This care has been integrated into dementia nursing homes, necessitating fewer hospitalizations of dementia patients. A study by The *et. al.* evaluated the decision making process regarding the course of treatment for patients with dementia in the Netherlands (2002).

The *et. al.* (ibid: 1326) found that in order to best understand the wishes of the patient, doctors created as broad a basis for communication and decision making as possible. This was achieved for the most part by involving the family and initiating discussions with all parties involved at different stages of the disease (ibid: 1328). What this treatment plan entailed was the building of

a relationship between doctor, patient and family members concerned. At some point, however, the responsibility of decision making fell primarily to a familial proxy as the demented patient lapsed into incompetence.

Multidisciplinary teams of healthcare professionals in the study reviewed the situation of each patient in the nursing home at six month intervals. Following an evaluation of prognosis and efficacy of present treatment, family members and proxies were invited to discuss the next six months of treatment with the doctor and the patient, depending on patient competence (ibid: 1328). At these meetings, treatment decisions were made based on:

- the medical condition of the patient;
- the wishes of the family;
- interpretations of the patient's quality of life, and
- any previous wishes of the patient (ibid: 1326).

It is obvious from this study that a good doctor-patient relationship is very important when dealing with treatment for a progressive disease like dementia. The results of programmes in which good communication is emphasized are notable: family members feel relieved upon receiving information which helps them decide about the future of a loved one. In addition, as Hertogh (2006: 555) notes, healthcare workers feel encouraged to address the subject of advance care planning with patients and proxies.

The wishes of the patient, as previously articulated to family and doctor, are important. The same is true of the opinions of family and proxies, who have close personal knowledge of the patient. For a doctor to offer a dementia patient the most favorable, personally acceptable care, it

is important that the doctor has as much information about the patient as possible. As shown in this section, this is generally obtained as a result of a good doctor-patient relationship.

The fact that the Dutch medical personnel mentioned in this section take a great deal of care to communicate adequately with their patients suggests that the doctor-patient relationship is important to medical personnel in the Netherlands; furthering findings related to specific objective C. Unfortunately this cannot be generalized to other countries, but it provides a fair indication of the attitudes of some medical personnel. In this case, medical personnel have recognized the need for good care and communication; and they have responded to it.

3.2.6. Tube Feeding and the Doctor-Patient Relationship

In their study, The *et. al*. (2002) aimed to determine the decision making process behind withholding the artificial administration of food and fluids in incompetent patients. Some of their results have been considered in Section 3.2.5 regarding treatment for patients with dementia. In these cases the patient's family was warned at the outset that the time would come when a decision regarding artificial feeding would be necessary. When it comes to dementia patients, this decision was generally made by the familial proxy in conjunction with the attending doctor (ibid: 1237). An example noted by the authors (ibid: 1239) provides an illustration of this method of decision making in action.

Mrs. J is a patient with moderate to severe dementia. In a conversation with her doctor, Mrs. J's daughter, Prudence, notes that Mrs. J's condition has been getting steadily worse. Prudence states that her mother "hasn't recognized [her] for some time now." The doctor adds that the nursing staff have noticed that Mrs. J is having great trouble swallowing. This is confirmed by

Prudence who comments on her mother's weight loss and her apparent inability to swallow the sweets "she loves so much."

The doctor reminds Prudence that although they are currently mincing up all Mrs. J's meals as well as giving her extra protein, the time will come when she will need to be fed artificially through a tube. Prudence answers: "No. My mother would never have wanted that. She always said that she didn't want to be kept alive. No, no tubes." Mrs. J's doctor agrees, noting that the dementia has now progressed to the stage that tube feeding would only be prolonging the inevitable. It is agreed to place Mrs. J onto a palliative care regimen, giving her all nutrition she can take orally as well as controlling any pain she appears to experience.

In this situation conversation between doctor and proxy reveals certain preferences on the part of the patient. The doctor is unlikely to find out about such preferences in the absence of contact with family members and proxy decision makers. The decision not to tube feed here is based on Prudence's conviction that her mother would not have wished to receive artificially administered nutrition. Prudence's guidance, and the fact that Mrs. J's doctor took the time to enter into conversation with her, will help ensure that Mrs. J receives treatment which is in accordance with previously expressed wishes.

Specific objective C has been addressed above. It shows that ongoing communication and relationship with the relevant proxy, given the incompetence of the patient, is something that the doctors participating in The *et. al's* study held in high esteem. Through this relationship, patients and their families receive the benefit of detailed information and participatory decision making which adds to a sense of security regarding treatment and enhances trust in the doctor.

3.2.7. Intensive Care and the Doctor-Patient Relationship

In their 2002 study, Way *et. al.* examine empirical research concerning the process of decision making in Intensive Care Units.[15] They focus especially on the decision making process *a propos* the withholding or withdrawing life support (ibid: 1342).

It is noted that families of critically ill patients in ICU often rate communication with doctors as among their most important and urgent concerns. This is often considered more important than clinical skills (ibid: 1345). Families felt reassured, and experienced greater peace of mind, when they felt that questions put to the doctor were answered honestly and articulated in an understandable fashion, pitched at the level of the family rather than that of other medical professionals (ibid).

In a literature search, the authors found that empirical research had shown that doctors have a poor understanding of patient preferences. Patients were also unlikely to discuss preferences for ICU treatment with their doctors (ibid: 1342). Another study showed that doctor's predictions of patient treatment preferences were only mildly better than chance (ibid). It was also found that some doctors make inaccurate assumptions regarding treatment preferences according to a patient's age or quality of life (ibid).

Over and above inaccurate predictions for care on the part of doctors, it was found that there was a good deal of disagreement regarding treatment between concerned parties. One study of patients for whom withdrawal of life support was being considered revealed the following conflicts: staff and family had conflicting opinions in 48% of cases, staff members conflicted with each other in 48% of cases and family conflicted with each other 24% of the time (ibid: 1343).

[15] Hereafter referred to as ICU(s)

Further complicating treatment decisions in ICU was the apparently stunted communication ability of some doctors (ibid: 1345). A study evaluating doctor-family meetings found that families did not understand basic features of the diagnosis, prognosis or treatment 54% of the time (ibid). Furthermore, research regarding resuscitation discussions found that the doctor talked 75% of the time, thus missing important opportunities to allow patients and families to voice their opinions or discuss goals for treatment (ibid).

Given the fact that some ICU doctors are both unfamiliar with patient's treatment preferences and are unable to communicate adequately, as well as the conflict which arises when it comes to proxy decision making, it has been found that the best way to resolve conflicts is to build on communication, negotiation and consensus building (ibid). The way to resolve conflicts is to build a relationship. An example of this process of decision making as it is used in ICU can be found in Appendix 1. This model necessitates that the ICU doctor spend time with the family and healthcare team in order to discern the most appropriate course of treatment for the patient.

This section has dealt with the idea of doctors trying to ascertain the treatment preferences of their patients. Their decisions may be considered a barrier to communication between patients and doctors – specific objective D. This is because doctors believe their decisions are accurate, thus somewhat obviating the need for communication. Here it has been shown that doctor's decisions are not always accurate. This means that actual communication could be helpful.

3.2.8. Schizophrenia, Mental Disorders and the Doctor-Patient Relationship

In a news article for the *British Medical Journal*, Mayor (2002: 1317) summarizes the position of the National Institute for Clinical Excellence[16] regarding treatment decisions for people committed into mental institutions or with mental disorders like schizophrenia.

NICE recommends that people with mental disorders should be involved in all discussions regarding their treatment plan and healthcare. It also advises that such patients are offered not only regular drug therapy but also psychological treatment (ibid). NICE advocates that "health professionals should work in partnership with services users and carers" and that they should offer help, treatment and appropriate care in an atmosphere of "hope and optimism" (ibid).

There is an emphasis on the need for proper joint decision making and informed consent in all forms of schizophrenia care (ibid). It was recommended that informed consent and joint decision making would best be achieved if the patient was in a more proactive mental state. Thus the recommendation was that psychotic patients were only moderately medicated with antipsychotic drugs rather than the high doses, favored in the past, which often led to lethargy and unassertiveness (ibid).

Although relationships with schizophrenia patients may be challenging, they are not overly so. It is important to remember that these patients may also desire some say in their treatment plan. It is easy in theory to allow this as it is generally quite obvious whether a patient is in a manic or normal phase. Treatment decisions for manic phases can be discussed and recorded during normal phases. Here it is once again very important for the healthcare team to spend time with the patient and ensure that treatment plans are agreeable to all parties.

[16] Hereafter referred to as NICE

Given that schizophrenia sufferers fluctuate between manic and normal phases it is important and relevant that they have a say in their treatment whilst in a normal phase; and that their wishes are respected, especially when in a manic phase. The study presented here suggests that a good relationship with psychiatrists and other healthcare professionals is valued by patients with this kind of mental disorder, especially when in a stage of relative normality. These results relate to specific objective C.

3.2.9. Diagnostic Testing and Results; and the Doctor-Patient Relationship

In their study entitled *Patient-Centered Communication and Diagnostic Testing*, Epstein *et. al.* (2005: 415) concluded that better communication between doctors and patients was associated with fewer diagnostic tests and decreased expenditures, but also with increased visit length.

This study was undertaken because of concerns that patient-centered medicine might lead to an increase in healthcare costs (ibid: 416). Other concerns were that spending more time with each patient decreased the number of patients who could be attended to on a daily basis.

Patient-centered communication can be of great benefit to the patient in cutting costs of testing and it helps the patient build a relationship with his or her doctor, increasing the probability of future treatment decisions being in line with patient preferences.

When it comes to specific objectives C and D, it becomes evident that over-zealous testing on the part of the doctor may hinder, rather than help, communication. Thus, it could be seen as a barrier. This could be as the result of a feeling that if there are going to be tests, communication is unnecessary. Clearly communication which leads to fewer diagnostic testing procedures is beneficial to the patient in a physical, mental and material sense.[17]

[17] The physical benefit is fewer painful or invasive tests. The mental benefit regards peace-of-mind. Patients find the waiting period for test results nerve-wracking and sometimes traumatic. The material benefit regards

3.2.10. HIV / AIDS and the Doctor-Patient Relationship

AIDS patients will also have to consider end-of-life care, generally as a result of an AIDS related illness.

A study by Curtis and Patrick (1997) explored barriers to, and facilitators of, communication regarding end-of-life treatment for AIDS patients. The AIDS patients voiced concerns common to those noted by patients with other diseases, such as discomfort when it came to talking about death and dying (ibid: 736). Two barriers unique to communication with AIDS patients were found:

- Some AIDS patients felt that talking about death may cause harm or even hasten the dying process (ibid). This was because many patients felt that their HIV was some form of punishment from God for being promiscuous or experimental with IV narcotics. Imminent death was to be borne in a stoical manner and should not be bought out into the open (ibid: 739).

- Many AIDS patients had experienced previous discrimination in the healthcare system based on their HIV positive status (ibid: 736). They were now unwilling to discuss their HIV status, and preferences for treatment, as there was a fear of further discrimination (ibid).

The conclusion of this study was that in order to improve quality of care at the end of life, it was also necessary to improve quality of the doctor-patient relationship at the end of life (ibid). It was found that a good relationship, based on thorough communication, went hand-in-hand with

finances. The financial benefit of fewer diagnostic tests means that doctor-patient communication may be especially valued by those in lower income groups. It is surprising that it is not initiated as a norm in state-funded practice as it appears good doctor-patent communication may prevent wanton waste of tax resources.

good end-of-life care. Hence it was important for HIV doctors to overcome the barriers to communication identified in the study (ibid). Because AIDS is stigmatized, doctor-patient communication can become very difficult and it must be handled with great sensitivity.

Curtis and Patrick's study deals specifically with barriers to, and facilitators of, doctor-patient communication amongst AIDS patients. Hence it is of most relevance to specific objective D. The fact that AIDS patients fear stigmatization and discrimination suggests that, though they would value communication opportunities – specific objective C - they fear the consequences of being open with doctors regarding HIV positive status.

3.3. Specific Objectives C and D

In this section I will very briefly summarize my findings regarding specific objectives C and D:

C. To evaluate the perceived importance of the doctor-patient relationship according to patients and medical personnel.

D. To discuss some barriers towards end-of-life discussions, and the unwillingness, on the part of both doctors and patients, to talk about death.

3.3.1. Specific Objective C: Evaluating the Perceived Importance of the Doctor-Patient Relationship According to Patients and Medical Personnel

In Section 3.2 I have shown that doctor-patient discussions are considered important to patients and to doctors.

Literature on the benefits of a good doctor-patient relationship from the patient's point of view has been considered. These benefits can be summed up as a more positive attitude on the part of patients regarding their disease and its treatment. Good communication leads to growing

confidence and trust in the doctor. I have also examined the negative consequences of a poor doctor-patient relationship from the patient's perspective, especially in Sections 3.2.4, 3.2.7 and 3.2.8. All studies and articles considered in Section 3.2 suggested that a good relationship with the doctor was of great importance to patients and should be prioritized.

The conclusion that a good doctor-patient relationship is also considered important from a doctor's perspective is more implicit in this literature. Studies regarding dementia and tube-feeding focus on the communicative strengths of the doctors concerned. These doctors have identified their relationships with patients as a necessary component of treatment. It can be inferred that these doctors believe that the benefits accruing to patients as a result of a good relationship between patient and doctor are important.

Although it cannot be claimed that all patients value the benefits of a solid relationship with their doctor, or that all doctors consider this to be important, the literature review has shown that it is symbiotically beneficial in a majority of cases. A patient benefits from open communication with his or her doctor and the doctor in question similarly benefits from a high level of patient satisfaction and esteem.

3.3.2. Specific Objective D: Identifying some Barriers Towards End-of–Life Discussions and the Unwillingness to Talk About Death

Throughout Section 3.2 many barriers to communication regarding end-of-life discussions were identified:

- When it comes to the elderly, a perception that older people - *ipso facto* closer to death – wished to avoid the subject was considered the most common barrier to communication.

Another barrier was the fact that there is a general unwillingness to talk about death, although this barrier does not effect communication with elderly people only.

- Physical barriers to communication were identified and it was suggested that more innovative communication styles were required to overcome these.
- Doctors' confidence in their own assessments for patient care was also cited as a barrier to good communication, given the fact that these were often incorrect.
- AIDS patients expressed unique barriers to communication relating to superstition and fear of discrimination.

It is evident here that there are several barriers to communication. There may be many others that have not been identified in this study. What becomes clear is that in order for patients to receive the benefits of good doctor-patient communication, and hence a good doctor-patient relationship, these barriers must be overcome by conscious effort on the part practitioners.

3.4. Ethical Analysis

I have considered the doctor-patient relationship in Section 3.2 of this chapter, and concluded that:

- The notion is considered important to both patients and medical personnel alike; and
- There are numerous barriers preventing the proper implementation of communication between doctors and patients.

I will now consider whether or not a good doctor-patient relationship enhances the ethics of medical practice and whether the process as a whole is ethically justifiable. The ethical analysis of the doctor-patient relationship will be in accordance with the theory of Principlism.

3.4.1. Is the Doctor-Patient Relationship Ethical? – Principlism

3.4.1.1. Introduction

Principlism was developed by Americans Tom Beauchamp and James Childress in the 1970s (Carter 2008: 2). It has today become a mainstream ethical theory and is widely applied to biomedical dilemmas (ibid). Principlism gives four *prima facie* obligations: autonomy, beneficence, non-maleficence and justice (Mallia 2003: 131). The relative importance of these principles is dependent on the moral and ethical (and other, possible religious) values of the agent making a decision (ibid). In medicine the agent is usually a doctor.

3.4.2. Autonomy

3.4.2.1. Introduction

Over the decades, respect for patient autonomy has come to be considered an integral part of the doctor-patient relationship (ibid: 2). Its recognition has primarily come about in reaction to atrocities of the past. Most notable of these were the horrendous human rights violations of Nazi concentration camps during World War Two. The Nuremberg Code, ratified after the end of the war, is the documentary culmination of the trials, in Nuremberg, of doctors and scientists who committed crimes against humanity during the war (2007 (b): 696). The Nuremberg Code enshrines autonomy: “The voluntary consent of the human subject is absolutely essential” and

the medical subject (patient) "should be so situated as to be able to exercise free power of choice" (ibid).

Autonomy can be defined as "The capacity, right, or actual condition of self-government, or the determination of one's own actions" (Feinberg and Shafer-Landau 2002: 776). In order to exercise autonomy, then, one must act without outside influence in the form of coercion, manipulation and duress. In order to act in this manner, one must be familiar with all the circumstances surrounding a particular decision. If there is a lack of pertinent information an action cannot be labeled autonomous.

3.4.2.2. Autonomy and the Doctor-Patient Relationship

In medicine, autonomy is prized very highly. It is the principle guiding informed consent, which has become an integral aspect of all medical treatment. In order to uphold and promote patient autonomy, informed consent is a mandatory requirement. Informed consent involves familiarizing the patient with his or her condition, as well as explaining possible treatments in great detail, including the risks, benefits and social and psychological consequences. This is best achieved (possibly only achieved) through good doctor-patient communication, which is brought about by a good doctor-patient relationship.

Consider the following example, adapted from Professor D. J. McQuoid-Mason (2008: Handout). Sarel, a high-flying entrepreneur with little interest in anything but profit is suffering much pain. In spite of his work pressures he consents to simple, exploratory surgery under general anesthetic in order to examine a possibly malignant growth in his abdomen. Sarel can recover from this simple procedure over the weekend and be back at work on Monday. During the procedure, however, the growth is found to be highly malignant. The surgeon takes the

decision to excise the tumor along with some of the secondary growths in Sarel's glands. Had the malignant tissue not been removed, Sarel's life expectancy would have been reduced to one year.

As a result of the surgery, however, workhorse Sarel must now take three months off. It is estimated that during this time Sarel will lose R1m in profit due to the fact that he will be unable to complete a contract. Sarel is outraged. He claims that had he known his tumors were malignant and he would be requiring major surgery he would have postponed it until the contract was complete in four months time.

It is quite clear that Sarel's autonomy was infringed by the surgeon who did not obtain informed consent for the major tumor excision surgery. Sarel lost his ability to be self-determining, even though the surgeon in question may have been acting with Sarel's best interests at heart. Had the surgeon taken more time to communicate with Sarel, and explore all the eventual outcomes of the exploratory surgery, Sarel would not be in this disadvantaged position and the surgeon would not potentially be facing a law suit.

It is evident from this example that a good doctor-patient relationship is vital when it comes to furthering patient autonomy. This relationship entails communication, and communication means that the patient will be aware of his or her options and that the doctor will not act against the patient's wishes. In order to know those wishes and act on them, thus leaving autonomy intact, conversation and relationship are paramount. By the principle of autonomy, then, the doctor-patient relationship is ethically sound and therefore desirable.

3.4.3. Beneficence

3.4.3.1. Introduction

According to Mallia, beneficence comes about as a result of the doctor-patient relationship (Mallia 2003: 2). A patient generally consults a doctor with the expectation that some good will ensue (ibid). This may be in the form of physical relief, psychological support or encouragement. Such benefits are referred to as "the good" or "good" in the paragraphs below.

According to Frankena (cited in Van Bogaert 2007 (c): 96) the principle of beneficence is normative. It says that:

- One ought not to inflict evil or harm
- One ought to prevent evil or harm
- One ought to remove evil
- One ought to do or promote the good of one's patient.

3.4.3.2. Beneficence and the Doctor-Patient Relationship

In order to promote beneficence, a good doctor-patient relationship is necessary.

Returning to the example of Sarel: A communicative relationship in this case would have served to prevent harm. It would have familiarized Sarel's surgeon with his wishes for treatment. It is important to remember, however, that Principlism is a set of *prima facie* obligations and as such the principle of beneficence must be weighed against the other principles.

The surgeon may well have infringed Sarel's autonomy; however he believed that he was doing good for his patient by removing the tumors. This is not necessarily the case. For someone driven by financial gain, a million rand contract may be far more important than physical wellbeing. Had the surgeon communicated with Sarel, he would have been promoting both

autonomy and beneficence. Under Sarel's ranking of the principles, the opportunity to postpone the surgery was the good, as it would have allowed him to pursue his autonomous objective of carrying out the contract.

It is evident here that a good doctor-patient relationship allows for and promotes beneficence. Without the communication that comes as part of this relationship, a doctor would not be aware of what his or her patient considers "good" and would then not be able to act in a beneficent manner towards that patient.

3.4.4. Non-Maleficence

3.4.4.1. Introduction

The principle of non-maleficence is commonly considered to be enshrined in the Hippocratic Oath (ibid: 97). It is conventionally thought that this part of The Oath commands us to "*Primum non nocere*" – First Do No Harm (ibid). The Oath does not actually advocate against doing harm to this absolute extent. Rather it advises us, in the words of Gillon, to "abstain from doing whatever is deleterious and mischievous" (ibid). In medicine it is important to remember that sometimes doing harm is necessary in order to do good.

3.4.4.2. Non-Maleficence and the Doctor-Patient Relationship

In the case of Sarel, the surgeon removes malignant tissue, inflicting harm on Sarel's physical self as well as his financial self. The surgeon, however, believed he was doing good. This is an example of conflicting *prima facie* obligations. The surgeon decided that the benefit accruing to Sarel as a result of the excision was sufficient to outweigh the harm he would suffer as a result of the surgery. This surgeon may have considered his action to be beneficent; however the failure

of informed consent in this case renders it more paternalistic than beneficent. So the surgeon considered beneficence to be his ultimate *prima facie* obligation in this case. By acting in the manner he did, the surgeon infringed the two most important *prima facie* obligations according to Sarel, namely autonomy and non-maleficence. Had the surgeon taken time to communicate with Sarel, the result here may well have been different. Both would have had a chance to voice concerns regarding treatment and a consensual treatment plan could have been devised.

A good relationship with patients will help a doctor gauge the amount of risk a patient is willing to accept for the benefits of treatment. Subjecting the patient to more risks than he or she is willing to take on is doing harm, even if the medical benefits of such actions are substantial. Thus it can be concluded that the doctor-patient relationship enhances the principle of non-maleficence as it helps ensure that the patient has a good understanding of the risks and benefits of different treatments and gives an informed consent on this basis.

3.4.5. Justice

3.4.5.1. Introduction

In the context of healthcare, justice is related to the concept of allocation of scarce resources (ibid: 98). It conflicts with the Hippocratic Oath, which advocates that one should do the best one can for every patient (ibid). Justice entails that due to resource scarcity, some patients and conditions may take priority over others. The big question is, how does one decide who should benefit from scarce resources? Is it just to allow an alcoholic to undergo dialysis while at the same time refusing an innocent child the same treatment? Who should take priority when it comes to scarce resources?

3.4.5.2. Justice and the Doctor-Patient Relationship

The doctor-patient relationship could be seen as a scarce resource. Developing it is a time-consuming process. Whilst a doctor is having lengthy discussions with one patient, other patients who would benefit from her medical attention are losing out. There is a tradeoff between the amount of time a doctor spends building a relationship with her patients and the number of patients she can attend to. They are inversely proportional: a stronger relationship, requiring more communication, implies fewer patients.

Unlike autonomy, beneficence and non-maleficence, the ends of justice are not necessarily furthered by the promotion of a good doctor-patient relationship. Justice may be better served by focusing less on individual relationships and attending to a greater number of patients. Justice can be viewed from two aspects here and it is for each doctor to decide their relative importance.

1. It may be considered more just to treat fewer patients in a thorough and thoughtful manner. This involves building a relationship with them, thus furthering the principles of autonomy, beneficence and non-maleficence. Or,

2. it may be considered more just to treat a greater number of people at the expense of promoting the three other medical principles and the doctor-patient relationship.

Justice, then, does not conclusively advocate for or against the doctor-patient relationship.

3.4.6. Ethical Analysis - Conclusion

It is clear from this analysis that a good doctor-patient relationship is ethically relevant according to the principles of autonomy, beneficence and non-maleficence; and ambivalent under the principle of justice.

The weighting system by which doctor and patient judge the relative importance of the four *prima facie* principles dictates the extent to which the doctor-patient relationship will be an integral part of medical treatment. The doctor-patient relationship is important to three of the principles, and not irrelevant to the fourth; the process of relationship building helps further all the principles to some extent. It can be concluded that the doctor-patient relationship is morally desirable according to Principlism.

3.5. Conclusion

In this chapter I have explored the doctor-patient relationship. Starting with a study of published literature, I have examined specific objectives C and D. With regard to these objectives I have concluded that the doctor-patient relationship is significant to both doctors and patients. Patients find a relationship with their doctor particularly important should they be suffering from a terminal illness or a mental disease. I have also identified some barriers to doctor-patient communication and, in Section 3.3.2 suggested that new, innovative communication styles could help overcome these barriers, hence improving the doctor-patient relationship. An ethical analysis of the doctor-patient relationship according to the moral theory of Principlism has been undertaken.

I have concluded that a strong doctor-patient relationship is ethically essential. As this is the case it follows that the doctor-patient relationship should be, or should become, an integral framework for medical consultation and decision making.

Having now shown that my two primary concepts, namely the living will and the doctor-patient relationship, are ethically valuable and desirable, I will explain in Chapter 4 how the living will can enhance doctor-patient communication and the doctor-patient relationship.

Chapter 4: Living, Dying and the Living Will - Enhancing the Doctor-Patient Relationship

4.1 Introduction

In the previous two chapters, I have explored in depth the two central topics of this research, namely living wills and the doctor-patient relationship. I have concluded that each is morally acceptable and thus they should both be considered as integral to medical practice. In this chapter I will synthesize my findings from the previous two chapters. I will present an argument in favor of the living will as an instrument for enhancing the doctor-patient relationship.

I will begin by considering literature relating to this question. I will then consider the idea that the living will could be used to enhance the doctor-patient relationship based on my findings and conclusions from the previous two chapters. A selection of the medical conditions and / or interventions mentioned in Chapter 3 will be used to exemplify ways in which the living will could enhance the doctor-patient relationship. Finally, I will address specific objective E by suggesting an outline for a practical model of using the living will as a means of improving communication and thus enhancing the doctor-patient relationship. I will make suggestions as to how the living will could become more widespread and hence discussions more readily initiated.

4.2. Literature Review

4.2.1. Introduction

Few published studies and articles deal with the way in which the living will might help enhance the doctor-patient relationship. This section deals with those which I have managed to find. The first study to be discussed here is an editorial in the *British Medical Journal* entitled: *How Living Wills can Help Doctors and Patients Talk about Dying*. The second is an empirical study in *Age and Ageing* entitled: *Living Wills and the Mental Capacity Act: a Postal Questionnaire Survey of UK Geriatricians*. These articles emphasize a close inter-connection between the living will and doctor-patient communication which enhances the doctor-patient relationship. The third study

regarding this topic appeared in the *Journal of General Internal Medicine* and was titled *Barriers to Communication About End-of-Life Care in AIDS Patients*. This study found results contrary to those reported in the first two studies mentioned above.

4.2.2. How Living Wills can Help Doctors and Patients Talk about Dying

This editorial concerned itself with the link between living wills and the much publicized need for better doctor-patient communication regarding end-of-life care (2000: 1640 – 1641). It mentioned studies which found that many patients are confused by the notion of a living will, but would nonetheless welcome the opportunity to discuss end-of-life care (Emanuel 2000: 1640). As a document specifically related to end-of-life care, the invocation of a living will may facilitate an improvement in the quality and frequency of discussions regarding end-of-life care and death. Emanuel (ibid) notes that living wills are generally in the form of "worksheets" or templates. These worksheets could be used to help "reflection and deliberation, and for team building between the professionals, families and the patient."

Emanuel (ibid) further emphasizes the importance of communication in her editorial by stating that some elderly patients welcomed the opportunity to consider, and have some control over, the last chapter of their life. Discussion helps to ready proxy decision makers for their roles in making healthcare decisions on behalf of the patient. Discussions like this also give families a chance to talk about the end-of-life and to resolve personal matters. Emanuel (ibid) finally claims that "living wills [have come] to be seen as a vehicle for achieving greater wisdom and skill in a fundamental aspect of healthcare and a civilized approach to mortality."

4.2.3. Living Wills and the Mental Capacity Act: a Postal Questionnaire Survey of UK Geriatricians

This study was conducted amongst geriatrician members of the British Geriatrics Society. The reason why geriatricians were chosen as the study group was that they have the greatest exposure to patients facing end-of-life decisions (Schiff et. al. 2006: 116). Schiff *et. al.* (ibid) found that many of the geriatricians practicing in Britain had experience of the living will.

Many stated that the living will, in patients where it had not yet come into force, "aided discussions about end-of-life care" (ibid: 118). It was found that, in the case of 96% of patients and 76% of families, presence of a living will made it easier to broach and discuss the subject of death (ibid: 117). In these cases it was also noted that such discussions took place "without inappropriately increasing time spent with the patient or relatives" (ibid: 118).

This study also showed that, in some cases where a patient's living will had not been discussed with family and proxy decision makers, these parties misunderstood its terms and were unfamiliar with its procedures (ibid: 117). It was also found that proxy decisions for care showed greater agreement with the living will directives of patients in cases where the living will had been discussed with the patient, the doctor and the proxies themselves (ibid: 119). This suggests the importance of discussing end-of-life care as well as the contents of a living will.

4.2.4. Barriers to Communication About End-of-Life Care in AIDS Patients

In this study conducted by Curtis and Patrick (1997), which was mentioned in Chapter 3, the living will was found to hinder discussions between patients and their doctors (ibid: 736). This was because participants in the study believed that once their preferences had been documented

in a living will, discussion was not necessary: “When you do the papers it pretty well lays it out there. It makes it clear. You’ve written it down. End of discussion” (ibid: 738 - 739).

This same study found, however, that when the contents of a living will were discussed with family and patient, these discussions were considered “less threatening” and more important. Family members may well be sharing in a patient’s treatment decisions (ibid: 739). Discussions regarding the contents of a living will - with a family member present - were also useful in that they helped iron-out the possible ambiguous interpretations of treatment decisions expressed in the living will (ibid).

4.3. Case-Based Reasoning and Casuistry

Case-based reasoning entails that each philosophical case presented must be evaluated on its own merits rather then according to a set of rules. Decisions should be made on a case-by-case basis. In each case the benefits and risks must be evaluated and acted upon in a manner fitting the particulars of the case (Strong 1999: 395). Case-based reasoning is particularly useful when it comes to the study of bioethics and medical ethics. Medicine is a profession dealing with people, all of whom have specific, and varying, circumstances.

Case-based reasoning allows for the consideration of personal circumstances on their merits (ibid: 396). Casuistry proposes a *modus operandi* for doing so, by taking the case at hand and comparing it with one or more *paradigm* cases. These paradigm cases are ones in which it is quite clear what course of action should be taken (ibid).

4.4. Paradigmatic Cases, the Living Will and the Doctor-Patient Relationship

In this section I will consider cases in which the living will is introduced as a component of the medical consultation process, either by a doctor or by a patient. I will present four fictional scenarios, corresponding to some of the medical disorders mentioned in Chapter 3. In each case I will show how the living will could hypothetically improve communication and strengthen the doctor-patient relationship. I will argue in my conclusion (Section 4.4.5.) that cases such as this should be considered as *paradigmatic* and could be very useful for solving bioethical dilemmas by means of casuistic reasoning.

4.4.1. Cardiopulmonary Resuscitation and the Living Will

In 1994, Mandla, father of Tumi, was involved in a serious motor-vehicle accident. Paramedics at the scene did everything in their power to resuscitate Mandla and eventually his heart started beating. It was clear, however, that Mandla could not breathe. He was ventilated. Three years later, in 1997, Mandla was still on a ventilator. It had been decided that he had irreversible brain damage. As his closest next-of-kin, Tumi became Mandla's healthcare proxy. She made the decision to remove ventilator support in mid-1997 and Mandla died a few minutes later.

Having been witness to her father's situation, and having noted the emotional toll his accident and subsequent medical treatment had taken on her, Tumi made a living will in late-1997. Before she signed the living will she took it to her general practitioner, Dr. Mallone. Dr. Mallone had also treated Tumi's father and paid close attention to his medical condition after the accident. Tumi decided that talking to Dr. Mallone was necessary as it was recommended on the living will document. In her living will Tumi explicitly refuses CPR under circumstances where there is little or no hope of making a full recovery.

Now, in 2008, Tumi receives an annual phone call from Dr. Mallone. He invites her to meet him on a yearly basis to discuss her living will. During these discussions, Dr. Mallone informs Tumi of new medical treatments which she might like to consider. He also gauges changes in her attitude to CPR. Having been involved in Mandla's treatment after his accident, Dr. Mallone understands why Tumi has made a living will. He can sympathize with her concerns and he tries his best to aid her decision-making process.

The fact that Tumi is given the opportunity to discuss her living will on an annual basis greatly enhances her relationship with Dr. Mallone. Tumi trusts him. She is also secure in the knowledge that, should her living will suddenly take effect, Dr. Mallone is aware of her anxieties and convictions. This will allow him to proceed in a manner most fitting Tumi's wishes.

A living will which requires doctor-patient discussion before signature – for example, about a decision on CPR - could improve communication and enhance the doctor-patient relationship (See Appendix 2). The fact that the procedure is explicitly stated in the living will can be expected to draw a patient's attention to its important complexities. By making both doctor and patient aware of the difficulties around CPR, it is hoped that one of them will bring the topic into a discussion. This could then open the door to discussing other aspects of the living will and possible treatment decisions under different conditions.

4.4.2. The Elderly and the Living Will

Nigel is a resident in a retirement village and this year he is turning 68. Apart from the odd ache and pain, he is in good health. Given Nigel's proximity to other old people in the retirement village he has witnessed many deaths. He has seen some of his friends perish quickly, but in great pain. He has seen the agony of family members making decisions for an elderly mother or

father who is no longer competent to do so. He has seen that these family members often have no idea about the treatment preferences of their elderly relative.

Nigel does not wish for his life to be prolonged if he is in pain. He also wishes to spare his family the emotional grief of making decisions on his behalf. Although he has discussed his death with some of his friends, his medical knowledge is limited. He would greatly value some time with his doctor in order to express his preferences and better familiarise himself with the courses of action available to him.

A young researcher, Miguel, then comes to conduct research in the retirement home. He hands out copies of a living will to all residents who have agreed to be part of his study. Nigel receives a copy of the living will and fills in the questionnaire that came with it. He keeps the living will and it gets him thinking.

A few days later Nigel meets Dr. Lane, his doctor, for a general check-up. He takes the living will document with him. He has not signed it or filled it in as there is a recommendation that it is discussed with a doctor before signature. When he goes into Dr. Lane's office he presents the living will and asks to discuss it. Dr. Lane responds positively and with a tone of palpable relief in her voice. She had wanted to discuss end-of-life issues with Nigel for sometime now, but given Nigel's good health had found no easy way to bring up the topic.

During their conversation, Dr. Lane comes to know a lot more about Nigel, his life before the retirement home and his present circumstances. This knowledge better allows her to understand Nigel's reasons for making certain decisions regarding his health and future medical treatment. This interaction between Nigel and Dr. Lane makes both feel more at ease. Nigel trusts Dr. Lane

who, for her part, feels a closer bond with Nigel. After this encounter the two have a much more open relationship.

This example shows how a living will can enhance the doctor-patient relationship. Presenting a living will form to one's doctor can initiate discussion of sensitive issues which are often avoided. These discussions have positive knock-on effects, like improved trust and understanding between doctor and patient, all of which result in the eventual strengthening and solidifying of the doctor-patient relationship.

4.4.3. Dementia and the Living Will

Mbali is 65 years old and has recently been diagnosed with dementia. The disease is still in its early stages and the subtle changes are evident to only those closest to her. In spite of a convincing diagnosis, Mbali – like many other dementia patients – is in denial about her condition. She still feels normal, functions properly and thinks straight. Hence she is convinced that her doctor, Dr. Mbete, must have made a mistake in his diagnosis.

Mbali's son, Sipiwe, is a successful lawyer. In his field of work he is well aware that once his mother's dementia renders her incompetent it will be too late for her to express treatment preferences. Sipiwe worries that his mother is not accepting the reality of her disease. As a result she refuses to discuss her wishes for treatment with him and the rest of their family.

Sipiwe calls Dr. Mbete and voices his concerns. Dr. Mbete replies that Sipiwe ought not to worry; he has an idea which might help solve the problem.

During the following few weeks, at each of Mbali's visits, Dr. Mbete hands her a living will form and encourages her to look at it, ask him questions and express her concerns. He tells

Mbali that he encourages all his patients over 65 to make a living will or at least discuss their preferences with him.

Dr. Mbete's repeated references to the living will soon start paying off. Mbali comes around to the idea of recording her preferences for treatment. She is still unconvinced about her dementia, but she has accepted that action should be taken on her part 'just in case'. Dr. Mbete, having discussed the living will document with Mbali at great length and over a long period of time, is satisfied that he has properly gauged her wishes regarding her end-of-life treatment and care. Mbali does not want to be tube fed and at such a time as this may be necessary she requests palliative care with good pain control but no artificial nutrients.

Dr. Mbete suggests a meeting between Mbali, Sipiwe and himself so that they may all discuss her living will and treatment preferences. Throughout this process the relationship between Mbali and Dr. Mbete has been greatly enhanced. Mbali knows that she can trust Dr. Mbete and that he will have her best interests at heart when it comes to her future treatment. She also feels more at ease regarding dying now that she has expressed her concerns to others. Dr. Mbete feels empowered to treat Mbali in a manner which she has specified and he also feels that his extensive interaction with Mbali will better allow him to comfort and reassure her family as she nears the end of her life.

4.4.4. HIV and the Living Will

Dr. Lewis is a general practitioner with rooms in a large, public hospital. Many of his patients are HIV positive but given the stigma surrounding AIDS they do not like to talk about their condition. In a recent internet search, Dr. Lewis became aware of an HIV-specific Living Will document (See Appendix 3). With the permission of the authors, he had a simple information

leaflet about the HIV-specific living will translated into three local languages and placed them in the public toilet in his rooms. The leaflet encourages all HIV positive patients to request an HIV-specific living will document from Dr. Lewis should they want one[18]. It also notes that the living will can be discussed with Dr. Lewis.

The result of this action is that many of Dr. Lewis' HIV-positive patients fill in an HIV-specific living will. Even those who do not agree to sign it still benefit from discussions regarding end-of-life treatment with the doctor.

The overall effect of this stratagem is that Dr. Lewis' relationship with many of his HIV-positive patients is greatly enhanced. These patients come to understand that they are not going to be subject to discrimination. Talking about AIDS also makes these patients feel more in control of their condition. This feeling of control makes it easier to maintain a positive attitude.

4.4.5. Conclusion

This section has presented four fictional cases illustrating ways in which the living will could help enhance the doctor-patient relationship.

Can I now claim that these cases represent *paradigms* by virtue of their straightforwardness and common outcome: that the living will, when introduced into the medical consultation process, can help enhance the doctor-patient relationship?

[18] A situation like this needs to be handled with great sensitivity. Dr. Lewis cannot offer an HIV-specific living will to each of his patients as, if they happen to be HIV negative, it may look like discrimination on his part, or a judgement based only on physical appearance. It is much better then, when it comes to HIV, that patients introduce the topic rather than Dr. Lewis. He also has a good reason for placing the information leaflets in the public toilet – this way people may look at the leaflet and take one without anybody else knowing, or making assumptions, about it. Obviously, not everyone sees the leaflet, but this is the best that can be done in such a sensitive situation.

Paradigmatic cases require evaluation according to the maxims pertaining to them. When it comes to the four cases presented above, these maxims are fairly clear (Vieth 1999: 51):

- The wellbeing of the patient – which is amplified by the enhanced doctor-patient relationship.
- The wellbeing of third parties, such as family members or proxy decision makers. This is amplified by the enhanced relationship which results from the doctor or patient bringing the living will into medical consultation. It is also augmented by a more open relationship with the patient in which ambiguities regarding the patient's condition are clarified.
- The wellbeing of the doctor – which comes about as a result of an enhanced doctor-patient relationship. The doctor faces fewer difficult decisions when it comes to predicting treatment preferences for patients. The doctor can also be assured of the patient's trust and confidence.

The cases presented in Sections 4.4.1. – 4.4.4. can be considered good *paradigmatic* cases as they represent scenarios of unambiguous moral acceptability. This is because each case enhances the wellbeing of the three primary agents involved in the process of medical consultation: namely the doctor, patient and the patient's family.

Although these hypothetical situations are somewhat idealistic, they do pave the way for proposing a model by which all doctors and patients who wish to enhance their relationship may do so. This will be the subject of section 4.5.

4.5. Specific Objective E: A Practical Model

Specific objective E of this research is to propose an outline for a system by which use of the living will might become more widespread. This would then lead to the enhancement of the doctor-patient relationship for many.

What kind of system should this be? Such a system could have as its basis the following considerations:

- A living will is only valid if made in sound mind, so there is no point in making it available in palliative care dementia homes or ICUs.

- Making it available through general practitioners who build up a relationship with their client base over a long period of time would be constructive. It would allow for regular updating of the living will as well as regular discussion regarding end-of-life decisions.

- Having information about the living will freely available to the public in discreet settings (for example in practitioner rooms) would also be helpful. This information could suggest that the living will can initiate sensitive discussions and it could detail the benefits of an enhanced doctor-patient relationship.

- Information about living wills could also be made available in the rooms of doctors who service retirement homes and institutions caring for the aged. This research has suggested that old people would value the opportunity to talk about death and make a living will. They will also benefit from an enhanced doctor-patient relationship in this case.

It is clear that some kind of empirical research might be required in order to establish which of these proposals would be most effective when it comes to practically enhancing the doctor-patient relationship. I hope to one day do this research, perhaps as a PhD.

4.6. Conclusion

In this chapter I have combined my two prominent concepts – the living will and the doctor-patient relationship – to show how the former can enhance the latter. The final conclusions of this research are presented in Chapter 5, below.

Chapter 5: Conclusion

5.1. Introduction

This chapter is a summary of my findings in this research. In Section 5.2 I will present a brief summary of my overall argument and the conclusions thereof. In Section 5.3 I will conclude this research report.

5.2. Living, Dying and the Living Will: A Summary of Conclusions

In this research I set out to establish whether use of the living will could enhance the doctor-patient relationship.

Chapter 2 and Chapter 3 dealt with the two primary concepts of this research: the living will and the doctor-patient relationship. These chapters shed light on current thinking regarding these topics. Ethical analyses at the end of each chapter argued that both of the concepts are morally acceptable and that each could be utilized in order to promote, on the whole, ethically valid medical practice.

In Chapter 4 I presented a synthesis of my results from the previous two chapters. Here I drew on relevant observations and conclusions in order to present a series of four hypothetical cases, each of which demonstrated that the living will can be used to enhance the doctor-patient relationship. Following this conclusion I presented some ideas for a sustainable model by which the living will may enhance the doctor-patient relationship in a practical manner.

5.3. Enhancing the Doctor-Patient Relationship: Living, Dying and Use of the Living Will - Conclusion

We study medicine and practice as healthcare professionals. We become doctors, nurses, medical technicians, therapists, medical scientists and bioethicists all with one primary expectation: That we might do some good. We spend our time focusing on life, preserving it, sometimes at all costs. But the ultimate end of life, death, is often not duly considered until it is too late.

The living will deals with death, a subject which few wish to talk about and which, given its sensitive nature, is a difficult concept to introduce into a conversation. We view it with mixed emotions: those in great pain find relief in the idea of death. Those suffering depression or psychological disorder view death as a welcome escape from a life which has become unbearable. Most people, however, view death with fear. It is not confronted. The "out of sight, out of mind" approach is preferred. Given this attitude, too many people enter the final chapter of their lives feeling frightened, unsure, and that they are not in control of their destiny. People wonder if their wishes will be considered. For those who are not surrounded by loved ones, this can be a lonely and traumatic experience.

A good relationship with a doctor is very helpful. Doctors have medical expertise allowing them to understand the physical and psychological condition of their patients in a way that a family member may not be able to do. Most importantly, on an idealistic level, medical professionals want to do good.

A doctor who has had a good relationship with a patient who is now dying is in the position to reassure patient, family and friends that the right decisions are being made. Even if the loved one has not signed a living will, the fact is that somewhere, maybe 20 years ago, a doctor sat

down, brought out a living will, gained some insight, enhanced a relationship and took a little extra care.

Now, as this patient dies, there is a sense of relief. There is the bodily relief that comes when a life has taken its course; but also emotional relief. This death was not complicated. Everyone knew the wishes of the patient. Everyone agreed that decisions made would have been acceptable to the patient. There is a sense of ease about this death. Some of the most troubling aspects which death usually brings with it are not in evidence.

Good relationships and interpersonal communication have led to a more open, honest evaluation of life and the bodily deterioration that it inevitably brings. This has led to a good death. The closing of a chapter that could have been painful was instead more like the culmination of a sharing, understanding doctor-patient relationship; brought about by use of the living will.

Appendix 1

This example illustrates the way in which good communication between doctor and family, in the case of ICU care, can help resolve conflict between these parties. The example is taken from Way *et. al.* (2002: 1343 – 1344).

Ms R, a 52 year old woman with severe rheumatoid arthritis and chronic immobility, was brought to the emergency department. Her health was poor, although stable, until the morning of admission, when she became disoriented and lethargic. She was admitted to intensive care, where she was treated for septic shock secondary to decubitus ulcers and for acute renal failure. On the day after admission she was requiring increasing doses of vasopressor drugs and developed acute respiratory distress syndrome. Some members of the intensive care team became increasingly concerned about the "futile" care they felt they were providing. The patient's family requested that the medical team "do everything" to keep her alive.

The intensive care team arranged for a conference with the family. The attending physician asked the family to describe their understanding of the patient's condition. The family was far more optimistic than her physicians, thinking she had a 50% chance of recovery to her former state of health. The attending physician then asked the family to tell the team what Ms R was like as a person. The team learnt that she had always been full of energy and ready and eager to take on all challenges. They were thus able to appreciate her relatively good quality of life and role in her family.

The team then explained that Ms R's poor underlying health and immune suppression meant that she was unlikely to recover from the progressive septic shock. They explained that high quality medical care is defined both by improvement in health and, when improvement is not possible, by ensuring comfort. The family was unaware that most deaths in intensive care occur after withdrawing or withholding life support and, with that information, began to develop more

trust The team reassured the family that they had time to think everything over and that life support would continue for as long as the family believed it was what Ms R would want. They emphasized that withdrawal of life support did not mean withdrawal of medical and nursing care and that her pain and other symptoms would continue to be monitored and treated. The family felt supported by the team and relieved that they had not been pressured into accepting withdrawal of life support.

Ms R remained critically ill with multiple organ dysfunction syndrome and showed no significant improvement despite maximal therapy. After several days, the family decided that Ms R would not have wanted ongoing life support in this situation. The team explained the process of withdrawing life support. They informed the family that she would be unlikely to survive for more than an hour after withdrawal, although occasionally patients survive longer. The team also asked about spiritual needs and the family requested a chaplain.

Routine investigations were discontinued and all drugs were stopped except for morphine and lorazepam. Morphine and lorazepam were titrated to comfort during terminal ventilator discontinuation. Ms R's family returned to the bedside after her extubation and she died within 30 minutes. A chaplain was with the family when she died.

Appendix 2

Attached in this Appendix is the Living Will Document of the Living Will Society of South Africa. It is reproduced here with the kind permission of Mrs. Brigid Raw, Director of SAVES: The South African Living Will Society (2008). The instruction page of this living will states that it is "imperative" to discuss its contents with one's doctor. The actual will itself contains a DNR clause. This DNR clause pertains specifically to those whom have decided to forego cardiopulmonary resuscitation.

SAVES — THE LIVING WILL SOCIETY
DIE LEWENDE TESTAMENT VERENIGING
P.O. Box/Posbus 1460, WANDSBECK 3631 Tel: (031) 266-8511 Fax: (031) 267-2218

PLEASE READ CAREFULLY

INSTRUCTIONS

Three (or more) original Living Wills should be signed after careful consideration, by persons of sound mind, above the age of 18 years, in the presence of TWO witnesses. (Witnesses should not be relatives or beneficiaries in one's Last Will and Testament.)

It is imperative to share this decision with anyone who may have to implement the Living Will - family, close friends and your doctor - who, because you are a registered member, will receive the backup of the Society in any emergency situation involving your Living Will.

DOCUMENTS MUST BE LODGED AS FOLLOWS:-

1. Kept at home in a safe place for easy access by someone, other than yourself, in the event of your being unconscious, at which time the Living Will should be handed to those treating you.

2. Also kept at home for inclusion in your in-patient file should the need for hospital, nursing home or hospice ever arise.
   N.B. When signing the hospital consent form, the words..."Subject to the directions as stated in my Living Will"...should be written immediately before your signature. It is important to remember to bring your Living Will home with you when you are discharged from hospital, and to keep it ready should future visits be necessary.

3. Lodged with your doctor, after full discussion of the contents, so that in advance of the possible need, the doctor understands your directives. (Provide your doctor with a Sticker to be placed on your medical file cover.) Should there be no private doctor, arrangements can be made to have this copy filed in your out-patient file at any hospital. (Again provide the hospital with a Sticker to be placed on the cover of your medical file.)

4. Residents of Retirement Complexes/Old Age Homes: A copy of the Living Will should be handed to the Management or Clinic Sister of the establishment. (Remember to hand them a Sticker to be placed on the cover of your file.)

N.B. Living Wills should **not** be kept in a safe custody box, should **not** be attached to your Last Will and Testament, and should **not** be returned to this office.

Your WALLET CARD is not your Living Will. It is carried to alert anyone finding you unconscious to the fact that you have signed a Living Will. Please ensure that the names and telephone numbers of the person/s who have access to your Living Wills are listed thereon.

AVAILABLE IN AFRIKAANS ON REQUEST

THE LIVING WILL

TO MY FAMILY, MY PHYSICIAN AND ANY HEALTH AUTHORITY:

This **advance directive** is made by me

Full Name: .....
(PLEASE PRINT)

Address: .....

.....

.....

at a time when I am of sound mind and after careful consideration.

If the time comes when I can no longer take part in decisions for my own future, let this declaration stand as my directive.

If there is no reasonable prospect of my recovery from physical illness or impairment expected to cause me severe distress or to render me incapable of rational existence, I do not give my consent to having my dying process prolonged by artificial means, including any pacemaker, nor do I give my consent to any form of tube-feeding when I am dying; and I request that I receive whatever quantity of drugs and intravenous fluids as may be required to keep me free from pain or distress even if the moment of death is hastened.

DO NOT RESUSCITATE: I do not give my consent to any person's attempt at resuscitation, should my heart and breathing stop and my prognosis is hopeless.

This declaration is signed and dated by me in the presence of the two undermentioned witnesses present at the same time who at my request in my presence and in the presence of each other have hereunto subscribed their names as witnesses.

Signature: ..... Date: .....

N B: Witnesses should NOT be family members or your personal medical practitioner/s, nor should they be beneficiaries in your Last Will and Testament.

WITNESSES:

Signature:	Signature: .....
Name:	Name: .....
Address:	Address: .....
.....	.....
.....	.....

NOTE: Should they wish, any person has my concurrence to apply for a court order to ensure compliance with this directive should any medical practitioner or health authority refuse to give effect to it.

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Appendix 3

This Appendix contains a copy of the University of Toronto's Joint Centre for Bioethics "*HIV Specific Living Will"*. It is copied here with the permission of Peter Singer (2008), the document's creator. Instructions as to how this living will should be filled in are also included in the Appendix.

THE HIV SPECIFIC LIVING WILL

THE INSTRUCTION DIRECTIVE

The first part of the instruction directive is the Treatment Table. Please refer back to Chapter 3, "Information About HIV/AIDS Health Care Decisions," for descriptions of the health situations and life-sustaining treatments used in the Treatment Table.

For each of the health situations (found in the first column of the table), imagine that you are in the situation described, and then you develop a further medical problem that requires some life-sustaining treatment (found in the top row of the table). If you do not receive this treatment, you would die. If you receive the treatment, the chance that you will live depends on the nature of the medical problem. Even if you recover fully from the medical problem, you would return to the health situation you were in before you developed the further medical problem.

As an example, imagine that, at some future time, you suffer from moderate dementia. Then, you develop pneumonia requiring life-saving antibiotics. Without the antibiotics, you would die. With the antibiotics, your chance of surviving depends on the nature and severity of the pneumonia. Of course, even if the antibiotics were successful in treating your pneumonia, you would still have moderate dementia.

You should then decide whether or not you would want the particular treatment (antibiotics) if you were in this condition (moderate dementia.

TO COMPLETE THE TABLE

Write your treatment decision ("YES", "NO", "UNDECIDED," or "TRIAL") in the box for every combination of health situation and treatment.

Take the example from the previous page and imagine again that you suffer from moderate dementia. If in that situation you would want life-saving antibiotics, if they were the only hope of saving your life, you would write "YES" in the box found where the column marked "Antibiotics" and the row marked "Moderate Dementia" meet. If you would not want antibiotics in those circumstances, write "NO" in that box. If you are undecided, you would write "UNDECIDED."

One other option is possible. In some cases, it may be unclear initially whether a given treatment will be beneficial or not. In these cases, you may want to try the treatment for an appropriate period, usually a few days to a couple of weeks. During this time your doctors would monitor and assess the effectiveness of the treatment and determine how beneficial it was for you. If the treatment proved to be beneficial, it could be continued. If not, it could be stopped. If you wish such a treatment trial, then write "TRIAL" in the box. For CPR and surgery, a treatment trial is not appropriate because these treatments are given all at once in a short time.

Then, the rest of the boxes may be filled in, by imagining yourself in each health situation and that you require each of the life-sustaining treatments listed.

	CPR	Ventilator	Surgery	Blood transfusion	Life Saving Antibiotics	Tube Feeding
Current Health with Potentially Reversible Illness						
Chronic Illness with Physical Disability						
Mild Dementia						
Moderate Dementia						
Severe Dementia						

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