

# A proposed distinction relating to the medical use of the term 'quality of life'

## Introduction

The concept of 'quality of life' is widely used in medical decision-making to facilitate comparison between different medical treatment options. It has also been used by the courts in the legal analysis of decisions concerning the giving, or withholding, of medical treatment from incompetent patients (that is, patients who lack the capacity to consent). This article analyses the use of the concept with particular reference to situations where medical treatment is withdrawn from patients whose death is the foreseeable result of such a withdrawal.

Two types of quality of life judgements are distinguished: 'incremental quality of life judgements' and 'absolute quality of life judgements'.<sup>1</sup> Incremental quality of life judgements seek to estimate the difference, or increment, that a medical intervention will make to the quality of life of a patient, whereas absolute quality of life judgements seek to give a global, or absolute, measure of the quality of life of a patient at a particular moment in time. It is also argued that the concept of 'best interests' (as used in the context of medical decision-making) is logically dependant on that of 'quality of life'.

This article proposes that, for ethical reasons, absolute quality of life judgements should be avoided. This does not affect the use of quality of life judgements as normally encountered in clinical medicine, because these are incremental rather than absolute, and - though incremental quality of life judgements may be defined in terms of absolute quality of life judgements - it is shown that they do not logically depend on the ability to make such judgements.<sup>2</sup>

This article is divided into four sections:

Section 1 considers the concept of 'quality of life'.

Section 2 introduces the distinction between 'absolute' and 'incremental' quality of life judgements and discusses the relationship between them.

Section 3 analyses the relationship between the concepts of 'best interests' and 'quality of life'.

Section 4 draws some conclusions from the discussion.

## Section 1: The concept of 'quality of life'.

James F. Drane in his *Clinical Bioethics*<sup>3</sup> suggests that the concept of quality of life evolved in medicine to help bridge the gap between scientific medicine - with its preoccupation with the objective categorisation of diseases and their cure - and the lives of individual patients with their own particular experiences and value systems. The need for such a concept arose from a recognition that the same medical intervention performed on individuals with different life styles and values could have radically different effects on the lives of these individuals, it might be

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<sup>1</sup> The terminology 'absolute/incremental' is reasonably common in speaking of measure e.g. one might seek to ascertain either the absolute temperature of an object at a particular time or the increment or change in the temperature over time.

<sup>2</sup> This article had its origins in work carried out for an MPhil thesis submitted to the Philosophy Department at UCC and which was entitled "An alternative conceptual structure for the resolution of end-of-life problems involving Persistent Vegetative State (PVS) patients." The thesis is available online at: <http://homepage.eircom.net/~roche/>.

The argument of the thesis was firstly, that the grounds used by both the Irish and English courts to justify the withdrawal of life-sustaining treatment from PVS patients were too broad in that cases of non-terminally ill infants suffering from severe disability were not readily distinguishable on legal grounds from cases of PVS; and secondly, that this danger of a 'slippery slope' was primarily due to the acceptance by the courts of absolute quality of life judgements. A conceptual scheme was proposed whereby incremental quality of life judgements in conjunction with certain ethical principles deriving from the concepts of 'a good death' and 'personhood', were sufficient to enable the withdrawal of treatment from PVS patients to be justified whilst permitting cases of treatment withdrawal from non-terminally ill infants to be legally and ethically distinguished from cases of PVS.

<sup>3</sup> James F. Drane, *Clinical Bioethics* (1994), p.172.

beneficial in some cases but harmful in others. The admonition that a physician 'Do no harm' does not mean harm in some abstract sense but in relation to the individual patient; it requires an assessment of whether a proposed intervention - even though usually beneficial - will in fact benefit the particular individual patient. In an attempt to formulate this problem more clearly, medical interventions have been considered to affect a patient in two ways: they can affect his actual life span (the quantity of his life or, as usually described, his 'life expectancy') or his capacity to enjoy his life (the quality of his life).

In scientific medicine, as in all scientific investigations, the primary goal is to quantify in order that decisions and comparisons can be more readily made. The 'quantity of life' is, by its very nature, quantified: a proposed intervention will increase or lessen the individual patient's life by 'X' years. However, the 'quality of life' is a more elusive concept. Before any attempt at quantification can be made it is necessary to clarify the meaning of the term 'quality of life' - though some commentators<sup>4</sup> believe that this problem has usually been resolved in the reverse order, that is by prioritising the quantification (this being easier to resolve) over attempts to clarify that which is supposedly being quantified.

To attempt to discuss the various definitions of quality of life would lead too far afield. Suffice to say that not only is there no consensus amongst academic commentators in the medical journals, as to the definition of quality of life - indeed, the possible measures of quality of life are numbered in the hundreds, each, presumably, with its own definition; but there is considerable dispute as to its usefulness, *i.e.* as to whether it helps to add clarity to discussions of a difficult topic or whether its actual function is to add a veneer of objectivity to what is in fact a subjective judgement, thus functioning as a mask and obfuscating discussion. For example, a recent British Medical Association (BMA) discussion paper states: "Terms such as 'quality of life' are problematic because of the pejorative implication they may convey that some lives are less valued. Assessments of 'quality' are inevitably value laden and subjective. Even if we resist the terms, however, the concept underlies much of the discussion and decision-making at the end of life."<sup>5</sup>

Edlund and Tancredi in an article entitled "Quality of Life: an Ideological Critique" also suggest that the term is ill-defined: "The very nebulous nature of the phrase 'quality of life', the lack of serious attention to what it means, and the extraordinary variety of definitions it may include make it susceptible to that characterization most beneficial to the individual decision maker. ... Decision makers will shift their ideology of quality of life to suit their interests."<sup>6</sup>

Lest it be thought that this criticism might be dated, a recent article published in the *Journal of the American Medical Association* is considerably more hard hitting: "... a clear conceptual basis for quality-of-life measures is lacking, and the few attempts to develop models or operational definitions of quality of life have been woefully inadequate. ... We thus infer quality of life from a variety of indicators, many of which tell us something about life, but nothing about quality. The consequence of this confusion is that it is often impossible to know exactly what is being measured, ..."<sup>7</sup>

These quotations show that even within medical circles, there is considerable dispute as to the usefulness - and indeed the coherence - of the concept of quality of life.<sup>8</sup> Nonetheless it is a widely used concept in medicine and it

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<sup>4</sup> Alain Leplège & Sonia Hunt, "The Problem of Quality of Life in Medicine" (1997) 278.1 J.A.M.A., 47 at 47.

<sup>5</sup> BMA, *Withdrawing and Withholding Treatment: A consultation paper from the BMA's Medical Ethics Committee* (1998), p.11.

<sup>6</sup> Matthew Edlund & Laurence R. Tancredi "Quality of Life: an Ideological Critique" (1985) 28.4 Perspectives in Biology and Medicine, 591 at 604.

<sup>7</sup> Leplège & Hunt *op.cit.* p.47.

<sup>8</sup> The focus of the remainder of this article is on the drawing of a distinction in the use of the term 'quality of life'; the difficulties inherent in its definition are not pursued further.

plays a crucial, albeit implicit role<sup>9</sup> in the judgements, in both the *Ward* and *Bland* cases<sup>10</sup> - the notable exception being Lord Mustill's judgement in the *Bland* case where he stated: "The interest of the state in preserving the lives of its citizens is very strong, but it is not absolute. ... It has been suggested ... that the balance may also be tipped ... by the attenuation of the interest in preserving life, where the 'quality' of the life is diminished by disease or incapacity. ... This is the first step on a very dangerous road indeed, ..."11

As stated earlier, the term quality of life is used in everyday clinical medicine as an aid in considering whether medical treatment should, or should not, be given to a particular patient; the criterion being that if the proposed treatment does not enhance the quality of life of the patient, it should not be given.<sup>12</sup> However, in applying the term to decisions relating to the continuation of life-sustaining treatment a subtle change occurs; here the principle is interpreted as implying that if the quality of life is adjudged to be so poor as to be practically non-existent, and if medical treatment could not alter this situation, then life-sustaining medical treatment should not be given, or if being currently given, should be withdrawn.<sup>13</sup>

The courts followed this reinterpretation and used the concept of quality of life as a decision-making tool: the judgement that the overall quality of life of a patient was nil,<sup>14</sup> or at least minimal, being sufficient to trigger the decision to withdraw life-sustaining treatment including artificial nutrition and hydration (ANH). The judgement of Taylor L.J., in *Re J* is a good example of such a usage: "I consider that the correct approach is for the court to judge the quality of life the child would have to endure if given the treatment and decide whether in all the circumstances such a life would be so afflicted as to be intolerable to that child."<sup>15</sup>

One of the main contentions of this article is that this use of the term quality of life is quite distinct from its use in everyday clinical settings and that the distinction between the two uses is of considerable ethical importance. We now examine the proposed distinction.

## Section 2: 'Incremental' and 'absolute' quality of life judgements.

This section is in three parts. The distinction between 'incremental' and 'absolute' quality of life judgements is explained in (A) where examples of both types of judgement are given. The argument that incremental quality of life judgements do not require the ability to make prior absolute quality of life judgement is set out in (B). The ethical grounds

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<sup>9</sup> Many of the judgements rely on the concept of 'best interests'; the relationship of it to the concept of 'quality of life' is discussed in Section 3.

<sup>10</sup> The seminal cases concerning the withdrawal of life-sustaining treatment from PVS patients are, in English law, the *Bland* case (*Airedale N.H.S. Trust v. Bland*, [1993] A.C. 789) and, in Irish law, the *Ward* case (*In the Matter of a Ward of Court*, unreported, High Court, Lynch J., May 5, 1995; Supreme Court, [1995] 2 I.L.R.M. 401). These cases exemplify the use by the courts of the concept of quality of life to justify the withdrawal of medical treatment in situations where the patient's death is the foreseeable result of such a withdrawal.

The *Ward* case concerned a young woman who, during the course of a minor gynaecological operation, suffered cardiac arrests which caused severe brain damage. As a result she was left paralysed and unable to speak. She was unable to swallow and was fed by a gastrostomy tube. Her eyes were open and often followed people moving in her vicinity. The judgement of her doctors was that such behaviour was mainly reflex with only a minimal purposive content. She was diagnosed as being in a 'near-Permanent Vegetative State' and it was the opinion of her doctors that recovery was most unlikely. For over twenty years her condition remained essentially unchanged and in 1995 her family, believing that her continued medical treatment was causing her considerable distress, sought an order from the High Court that medical treatment, other than that of a purely palliative nature, be discontinued and that she be allowed to die.

The *Bland* case involved a court application for a declaration that the withdrawal of medical treatment including artificial nutrition and hydration (ANH) from a patient Tony Bland, was lawful. Tony Bland had been seriously injured in the Hillsborough football disaster. He suffered severe brain damage and was subsequently diagnosed as being in a PVS and was fed by a nasogastric tube. At the time of the court application he had been in this condition for three and a half years; the medical prognosis was that there was no hope of any recovery.

<sup>11</sup> The *Bland* case at p.894.

<sup>12</sup> e.g. a recent comment from the BMA states: "New guidance, 'Withholding and withdrawing life-prolonging medical treatment', builds on the central ethical principle that the primary goal of medicine is to benefit the patient. If a treatment fails or ceases to give a net benefit to the patient, it may ethically be withdrawn or withheld and the focus of medical effort will shift to controlling distressing symptoms and keeping the patient comfortable." (Press release issued by the BMA on 23<sup>rd</sup> June 1999 and entitled *BMA Publishes new ethical guidance on withdrawal of treatment*.)

<sup>13</sup> This usage possibly originated from attempts to assimilate the methodology used in making treatment decisions for terminally ill patients, into a quality of life framework.

<sup>14</sup> e.g. the evidence given by a consultant neuropsychiatrist in *Frenchay Healthcare NHS Trust v. S* [1994] 2 All E.R. 403 at 408: "His current quality of life is nil ...".

<sup>15</sup> *Re J (A Minor) (Wardship: Medical Treatment)* [1990] 3 All E.R. 930 at 945.

for arguing that absolute quality of life judgements are impermissible, are set out in (C).

#### A: The distinction between incremental quality of life and absolute quality of life judgements.

In an effort to remove some of the ambiguity associated with the concept of quality of life judgements two meanings will be distinguished: 'incremental quality of life judgements' and 'absolute quality of life judgements'.

##### Incremental quality of life judgements

Consider a proposed medical intervention on a particular patient - one of those normal everyday medical interventions, the very routine of any hospital. If one's purpose is to assess whether this intervention should be performed then it is necessary to judge whether it would improve the patient's quality of life; if it did so improve his quality of life, it should be performed, otherwise not. In other words, the clinician is required to determine the increment, or change - either positive or negative - which is expected to occur in the quality of life of a patient as a consequence of a proposed medical intervention. The intervention should be performed if, and only if, this increment is positive.<sup>16</sup> This would be in accord with the injunction to physicians often attributed to Hippocrates, "To help, or at least to do no harm."<sup>17</sup> I propose the term 'incremental quality of life judgements' to describe such judgements.

##### Absolute quality of life judgements

The concept of absolute quality of life relates to attempts to measure the total quality of life of a patient and adjudge that in certain cases the quality of life is so poor that they would, in everyday language, 'be better off dead'. Such an index or measure may be quite primitive - such as 'good', 'poor', or 'non-existent' - or may attempt a greater sophistication, but irrespective of its complexity it reduces quality of life to a linear scale by means of which comparisons can be made. I propose the term 'absolute quality of life judgements' to describe judgements made with the use of such indices. An example of the legal use of an absolute quality of life measure is found in the test proposed by Lord Justice Taylor in *Re J* "... whether in all the circumstances such a life would be so afflicted as to be intolerable to that child."<sup>18</sup>

##### Examples showing the differing uses of the term quality of life.

###### *Frenchay Healthcare NHS Trust v. S*<sup>19</sup>

The facts of this case were that a young man had taken a drug overdose which resulted in him sustaining severe brain damage; he was diagnosed as being in a Persistent Vegetative State (PVS) and necessitating tube feeding. Subsequently his gastrostomy tube had become disconnected and an operation was required to insert a new tube.

There appeared to be a conflict of evidence relating to the patient's quality of life. The patient's neuropsychiatrist gave evidence that the patient's quality of life was 'nil'; however, the expert in rehabilitative medicine disagreed and believed that there were respects in which his quality of life could be improved. She argued that this could be achieved by, for example, a reduction of the amount of sedation and by the use of a chair which would better

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<sup>16</sup> Situations where there is an expectation of improved life expectancy but decreased quality of life have been omitted for reasons of simplicity; their incorporation into the analysis presents no theoretical difficulty.

<sup>17</sup> *vide* Albert R. Jonsen, "Do No Harm: Axiom of Medical Ethics" in S. F. Spicker & H. T. Engelhardt (eds.) *Philosophical Medical Ethics: Its Nature and Significance*, (1977) p.27.

<sup>18</sup> *Re J* at 945.

<sup>19</sup> [1994] 2 All E.R. 403.

ensure the patient's comfort.

It is clear that that the neuropsychiatrist was using the term quality of life in the sense of 'absolute quality of life' whereas the consultant of rehabilitative medicine was using it in the sense of 'incremental quality of life' - thus emphasising the need to distinguish between these meanings and showing that what was interpreted in the judgement as a conflict of evidence, was in reality not so.

*Re B (A Minor) (Wardship: Medical Treatment)*<sup>20</sup>

This case concerned a Down Syndrome infant with an intestinal blockage which was removable by a simple operation, her life expectancy would then be 20 to 30 years. The child would die in a matter of days without the operation. The child's parents refused consent to an operation arguing that even if the operation was successful, the infant would have a minimal quality of life.

The distinction between incremental quality of life and absolute quality of life is crucial to the analysis of this case. The parent's position was that the absolute quality of life of the infant was minimal and accordingly that the operation should not be performed but it is equally clear that the operation would improve the incremental quality of life of the infant.<sup>21</sup> If improvement in incremental quality of life is accepted as the appropriate criterion for treatment decisions then it is clear that the operation should be performed.

*Re R (Adult: Medical Treatment)*<sup>22</sup>

R was born with a serious malformation of the brain and with cerebral palsy and he subsequently developed severe epilepsy. He was 23 years old at the time of the court application and had profound learning difficulties and had not developed any formal means of communication; he was believed to be both blind and deaf. He was unable to chew and his food had to be syringed to the back of his mouth. The only response to touch appeared when he was cuddled and he then gave an indication of pleasure. Dr. Andrews<sup>23</sup> gave evidence that R existed 'in a low awareness state.' R appeared to respond to pain and suffered from recurrent chest infections. R's consultant was of the view that, when the next life threatening crisis occurred, treatment should be withheld to allow R to die with some comfort and dignity. A 'Do Not Resuscitate' (DNR) order had been made by his medical carers with the consent of his family. R's carers at the day centre which he attended, did not agree that his quality of life was 'unacceptable' - a term used in the BMA guidelines on DNR orders - and sought the assistance of the Disability Law Service in seeking a judicial review. In response, the hospital authorities sought not only a declaration as to the lawfulness of the DNR order, but in addition a declaration that it was lawful to withdraw ANH; this latter application was later withdrawn and permission was sought to conduct a gastrostomy.

The question before the court was whether the DNR order was appropriate.<sup>24</sup> Evidence was given by Dr. Andrews that, in a hospital setting, cardio-pulmonary resuscitation (CPR) was effective for only 13% of patients and that, in a nursing home situation, the chances of a successful resuscitation would be almost nil; in addition there was the danger of the patient incurring either broken ribs or further brain damage.

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<sup>20</sup> *Re B (A Minor) (Wardship: Medical Treatment)* [1990] 3 All E.R. 927.

In the *Ward* case (at p.449) counsel for the Attorney General, referring to *Re B*, submitted that "... the case uniquely illustrates why the quality of life should not be adopted as a test." None of the judgements in the *Ward* case gave any detailed consideration to the decision in *Re B*.

<sup>21</sup> The same distinction is at the heart of the Canadian case *Re Superintendent of Family and Child Service and Dawson* (1983) 145 D.L.R. (3d) 610, and the English case *T (A Minor) (Wardship: Medical Treatment)*, *The Times* of 25th October 1996. In *T (A Minor)* - unlike *Re B* - the courts upheld the parents' contention that treatment be withheld.

<sup>22</sup> *Re R (Adult: Medical Treatment)* [1996] 2 F.L.R. 99.

<sup>23</sup> Dr Andrews is an expert on the diagnosis and treatment of PVS.

<sup>24</sup> The joint BMA and Royal College of Nursing (RCN) guidelines considered that a DNR order would be appropriate *inter alia* "... where successful CPR is likely to be followed by a lengthened quality of life which would not be acceptable to the patient." *Re R (Adult: Medical Treatment)* at p.102.

Giving judgement, Sir Stephen Brown P., - who regarded the evidence of Dr Andrews as crucial to his decision - allowed the DNR order to stand; however, he also placed reliance on a passage from the judgement of Taylor L. J., in *Re J*, when he stated: "The operative words in this passage ... are 'so afflicted as to be intolerable'. The extensive medical evidence in this case is unanimous in concluding that it would not be in the best interests of R to subject him to cardio-pulmonary resuscitation in the event of his suffering a cardiac arrest."<sup>25</sup>

It is suggested that the proposed distinction allows the arguments in this case to be more clearly analysed:

- (i) the consultant's assessment was an absolute quality of life judgement.
- (ii) the carers disputed this absolute quality of life judgement and in doing so also placed reliance on an incremental quality of life judgement in that they believed that their daily interactions with the patient gave him pleasure and comfort.
- (iii) Dr Andrews' assessment of the inappropriateness of CPR was an incremental quality of life judgement in that it was doubtful that CPR would have improved the patient's quality of life.
- (iv) The decision of the court placed reliance on both an absolute quality of life judgement (a life "so afflicted as to be intolerable") and an incremental quality of life judgement (Dr. Andrews' evidence). It is clear that the incremental quality of life judgement would have been sufficient to ground the decision of the court and that the *ratio* of the case should be so construed. However, the BMA analysis of this case sees it as authority for the use of absolute quality of life judgements: "In reaching this decision, the court adopted the 1993 guidelines published by the BMA ... which state ... 1. Non-treatment decisions should be considered in the following circumstances: ... (c) where treatment is likely to be followed by a quality of life which would not be acceptable to the patient. (The court also accepted an alternative wording of (c) which indicated that non-treatment could be based on 'unacceptable quality of life' but omitting the reference to the patient's own view. In R's case, he could form no view.)"<sup>26</sup>

### Terminal Illness

It was mentioned earlier that absolute quality of life judgements may well have originated from attempts to assimilate the methodology used in making treatment decisions for terminally ill patients into a quality of life framework. These treatment decisions for terminally ill patients are of two types:

- (i) The first type are those where the treatment can be justified in terms of improving a patient's incremental quality of life, even though the patient's life is shortened as a (possibly desired) side effect.<sup>27</sup> These are the treatment decisions spoken of by Lord Donaldson in *Re J* when he stated that the question that doctors have to decide is whether: " ... a particular decision as to medical treatment should be taken which *as a side effect* will render death more or less likely. This is not a matter of semantics. It is fundamental. At the other end of the age spectrum, the use of drugs to reduce pain will often be fully justified, notwithstanding that this will hasten the moment of death."<sup>28</sup>

This is an example of the classic double-effect argument; however, when cast into the language of incremental and absolute quality of life judgements, a new dimension is revealed. In suggesting that painkillers should be given to the terminally ill even at the risk of shortening their lives, Lord Donaldson was emphasising that giving of the pain killer itself required a justification, which was that it reduced pain and thus improved the patient's

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<sup>25</sup> *Re R* at p.108.

<sup>26</sup> BMA (1998) at p.13.

<sup>27</sup> It was mentioned earlier that for reasons of clarity, the interplay between 'quality of life' and 'quantity of life' has been omitted from this discussion.

<sup>28</sup> *Re J* at p.938 (emphasis in the original).

incremental quality of life; there is no absolute quality of life judgement involved in this type of case.<sup>29</sup>

- (ii) This contrasts with the second type of treatment decision which do not, and are not calculated to, improve the patient's incremental quality of life but are designed to allow him to die.<sup>30</sup> These are justified on grounds either of futility or that they serve the patient's best interests in that the patient is dying. It is clear that such judgements are absolute quality of life judgements. The double-effect argument is often employed in such circumstances to justify the withdrawal of treatment, and in so far as there are no incremental quality of life benefits it is clear that such applications are improper.

The conclusion that absolute quality of life judgements should be avoided on ethical grounds<sup>31</sup> would imply that treatment decisions for the terminally ill, which are of the second type should also be avoided. In dealing with such cases a wider conceptual framework is required such that death - and, in particular, the concept of 'a good death' - is given a central role in the analysis, such a framework would permit these cases to be resolved without the necessity of relying on absolute quality of life judgements.

### B: Incremental quality of life judgements do not depend on an ability to make absolute quality of life judgements.

Obviously if absolute quality of life judgements are possible - and ethically permissible - then a clinician could make an incremental quality of life judgement simply by making an absolute quality of life judgement for the circumstances that pertain before the intervention, and again for those circumstances which he believes will exist after the proposed intervention; the incremental quality of life being nothing more than the difference between the absolute quality of life after the proposed intervention and that before it.

However, - and most importantly - the ability to make incremental quality of life judgements does not depend on an ability to make absolute quality of life judgements. The fact that this is so allows one to accept the validity of incremental quality of life judgements whilst denying the validity of absolute quality of life judgements. If this was not so the attempted distinction between absolute quality of life and incremental quality of life, would be of little interest.

It is not being suggested that the concept of absolute quality of life is not relevant to the concept of incremental quality of life; still less is it being suggested that the concept of incremental quality of life is logically independent of that of absolute quality of life; what is being argued is that *changes* in absolute quality of life can be measured even though it itself either cannot or, for ethical reasons, should not be measured as a totality. An analogy explains the point clearly: imagine choosing a gift for a friend; one estimates which particular gift would give them the greatest happiness, one examines whether a particular gift would tend to increase or decrease their quantum of happiness and one chooses that which maximises the incremental increase; attempts to estimate the friend's total quantum of happiness are neither necessary nor desirable. Some very simple examples can also clarify the operative principle and obviate the necessity for an exhaustive explanation.

#### Example 1

Imagine a glass of water 'A' from which some water is removed by evaporation, leaving the glass as at 'B' in Diagram 1. If one wished to determine the amount of water removed then one could certainly measure the amount of water at 'A', then measure the amount of water at 'B' and then subtract these figures. This is illustrated below in

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<sup>29</sup> The irony is that in *Re J Lord Donaldson* justified the decision not to reventilate on *absolute* quality of life grounds - hardly compatible with calling the resulting death 'a side effect'.

<sup>30</sup> For example, decisions to withdraw ANH or ventilation, when not performed in order to remove a source of discomfort caused by the ANH or by the ventilation. R. A. Duff has suggested (in his *Intention, Agency and Criminal Liability* (1990) p.61 *et seq.*) that, in order to determine which of a number of consequences of an action could rightly be called the intended consequence of the action, we need only ask as to what must happen before the procedure would be adjudged to be successful.

Diagram 1.

If, however, one was unable to measure the total quantities in the glasses - imagine that a piece of card was placed in front of the glasses so that the total quantity was not determinable - then it would still be possible to determine the amount removed by comparing the levels both before and after the operation, provided only that one was sure that all else remained unchanged; hence, if the only change was that by evaporation, one could determine the amount evaporated. This is the situation illustrated below in Diagram 2.

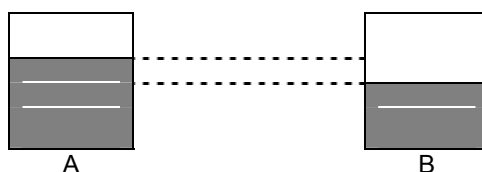


Diagram 1: Change can be measured by comparing the totalities.

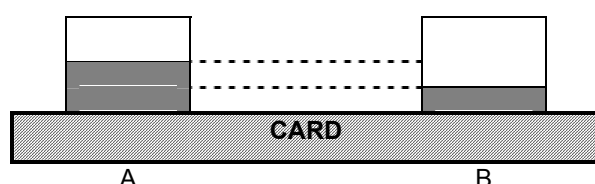


Diagram 2: Change can be measured even though the totalities cannot.

### Example 2

The problem is to measure the population increase of some country between, say, 1990 and 2000. Certainly, the population increase could be determined by measuring the total population in 1990 and again in 2000 and then subtracting these results. However, in the absence of such information the population increase could also be determined simply by noting the changes that have occurred - *i.e.* the births less the deaths (assuming these to be the only changes).

These examples show that it is possible to measure the incremental changes of a quantity without necessarily being able to measure the total quantity.

Returning to the original discussion, it is clear that a physician can judge whether (within the context of the life of a particular patient and judged from that patient's perspective) a proposed medical intervention will have a positive or negative effect on the quality of life of that patient, whilst at the same time fully accepting that he, the physician, is utterly unable to assess the quality of life - in the sense of absolute quality of life - of that patient; thus showing that incremental quality of life judgements do not depend on an ability to make absolute quality of life judgements.

### C: Absolute quality of life judgements should be avoided.

The argument against the use of absolute quality of life judgements is based on two grounds; firstly, that such judgements conflict with egalitarian principles, secondly, that they are unreliable.

### Absolute quality of life judgements conflict with egalitarian principles.

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<sup>31</sup> The arguments for this conclusion will be set out in (C).



In attempting to clarify the decision-making process in respect of the giving or withholding of medical treatment, the life of a patient is often described in terms of its quality and its quantity; however, the idea that a human life can be encapsulated in such terms can be a profoundly inegalitarian one.

If quantity of life is equivalent to length of life, then the statement that persons' lives differ in their quantity cannot be disputed. However, if it is conceded that their lives also differ in their quality, and that this difference can be measured, so that it is possible to state of two persons, which has the better quality of life, then it is difficult to avoid the conclusion that such lives differ in their worth. Consider two persons with an equal life-expectancy whose lives differ only in that one is judged to have a poor quality of life and the other a good quality of life; if the value of their lives can be wholly encapsulated in such judgements, then would it not follow that it was a lesser evil to kill the one with the poor quality of life or that it was a good to kill the former in order to save the latter?<sup>32</sup> This was the argument of Lord Mustill in the *Bland* case, when he rejected the suggestion that the quality of a life is diminished by disease or incapacity because it would imply that "... one life is intrinsically worth less than another."<sup>33</sup> It was also the argument of the Attorney General when, in the *Ward* case, he submitted that if the State were ever to take quality of life considerations into account then this would imply that it need provide less protection for the most disadvantaged or most vulnerable of its citizens - the very citizens who had most need of its protection.<sup>34</sup> Mr Justice Egan in his dissenting judgement in the *Ward* case, appeared to share these views: "Cognition in a human being is something which is either present or absent ... Any effort to measure its value would be dangerous."<sup>35</sup>

To avoid these conclusions it seems necessary to allow that the quality of a person's life is, in a deep private sense, immeasurable; that between lives, quality is equal - 'equality' after all means the possession of a like degree of quality - and that this equality flows from their incommensurability rather than from any equality of measure. It is this perception that is manifested in the suggested prohibition on absolute quality of life judgements.

The recognition that the quality of life of any individual is, at best, opaque to others,<sup>36</sup> does not preclude the use of the term as an aid in deciding on an appropriate intervention. After all we share a common humanity and an awareness of what is likely to be of assistance to another. If the attempt to assist is done, not in a paternalistic sense of acting to 'better' or 'do good to' another, but rather from a sense of empathy<sup>37</sup> - by entering as far as possible into their world view and, from that perspective, assisting - then it could indeed be said to improve their quality of life but such a usage of the term is clearly in the sense of incremental quality of life rather than absolute quality of life.

#### Absolute quality of life judgements are unreliable

Two examples are offered which, I suggest, indicate the radical difference that can exist between the perception of quality of life judged from within a life, and from without.

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<sup>32</sup> This echoes Raskolnikov's argument in Dostoyevsky's *Crime and Punishment* when - in judging the (absolute) quality of life of an old but wealthy woman neighbour as poor - he reasoned that to kill and rob her would permit him an improvement in his quality of life sufficient to justify her murder.

<sup>33</sup> The *Bland* case at p.894.

<sup>34</sup> The *Ward* case at p.448: "He submitted that the quality of the ward's life is a question of judgement but that that judgement is impermissible to our courts."

<sup>35</sup> *ibid.* p.437.

<sup>36</sup> "We do not know - cannot know - what lies behind these invisible walls." David Tomkin & Adam McAuley "Re A Ward of Court: Legal Analysis" (1995) 1 M.L.J.I. 45 at 46.

<sup>37</sup> In Eastern philosophy the belief that morality has its origin in empathy rather than in rationality is common; it was also espoused by Schopenhauer: "... if I do you an injustice I am sinning against myself as well as you. This, said Schopenhauer, is the explanation of morality, because it explains the compassion, fellow-feeling, disinterested concern for others, ... Schopenhauer disassociates himself from Kant's doctrine that rationality is the foundation of ethics; ..." (Bryan Magee, *Confessions of a Philosopher* (1998) at p.482.)

### Jean-Dominique Bauby

In 1995, Jean-Dominique Bauby who was the editor of a French fashion magazine, suffered a severe stroke and, with the sole exception of his left eyelid,<sup>38</sup> was completely paralysed; yet he 'dictated' a book<sup>39</sup> by signalling with his eyelid, blinking once for 'yes', two for 'no' in response to a friend holding up cards on which the letters of the alphabet had been written. After his accident some of Bauby's former acquaintances had described him as 'a vegetable'. He had been told of this and had written his book partly as a response.

Shortly after the accident he described his appearance: "Reflected in the glass I saw the head of a man who seemed to have emerged from a vat of formaldehyde. His mouth was twisted, his nose damaged, his hair tousled, his gaze full of fear. One eye was sewn shut, the other goggled like the doomed eye of Cain. For a moment I stared at that dilated pupil before I realised it was only mine."<sup>40</sup>

But, if his body was trapped in the diving-bell of the book's title, his mind would take flight like a butterfly: "My cocoon becomes less oppressive, and my mind takes flight like a butterfly. There is so much to do. You can wander off in space or in time, set out for Tierra del Fuego or for King Midas's court. You can visit the woman you love, slide down beside her and stroke her still-sleeping face. You can build castles in Spain, steal the Golden Fleece, discover Atlantis, ..."<sup>41</sup>

The friend to whom he dictated the book has said: "He did not want to die. He had so many plans. He wanted to write another book and set up an association for people like himself. You cannot say he had nothing to live for. He loved life more than most able-bodied people."<sup>42</sup>

Bauby, speaking of his attitude to withdrawal of life-sustaining treatment, had said: "When the neurologist asked did I regret that I had been resuscitated, tell him that I don't think like that anymore but that I'm glad that he asked the question."<sup>43</sup>

### Viktor Frankl

Viktor Frankl was a survivor of the Nazi concentration camps who later became a noted psychotherapist and author. His reflections on how people managed to survive and to find a certain dignity even in Auschwitz, were published in his book *Man's Search for Meaning*.<sup>44</sup> In this book Frankl used his own experience of the concentration camps to show how meaning could be found in even the most appalling situations; he acknowledged that in many cases it took a degree of unscrupulousness to survive the degrading conditions of these camps but he was nonetheless strikingly impressed by the inner freedom created by the condition of possessing nothing: "I understood how a man who has nothing left in the world may still know bliss."<sup>45</sup>

### Inferences from the examples

A disinterested observer would surely have judged Bauby's quality of life to be non-existent and regarded the lives of the inmates of Auschwitz as of appalling grotesqueness, yet in both situations - when judged from within - life was not only possible but a good. It might be objected that no matter how persuasive these individual examples might be, they may well be the exception; and that normally the judgement of a life from within and from without are

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<sup>38</sup> A condition known as 'Locked-In', or Guillain-Barré, syndrome.

<sup>39</sup> Jeremy Leggatt (trans.), *The Diving-Bell and the Butterfly*, (1998).

<sup>40</sup> *ibid.* p.32.

<sup>41</sup> *ibid.* p.13.

<sup>42</sup> Quoted in *The Sunday Times* 16.3.1997.

<sup>43</sup> Quoted in a film on Bauby entitled "The Works" (BBC2, 18.5.1997).

<sup>44</sup> (1959).

<sup>45</sup> Quoted in his obituary in *The Times* 30.9.1997.

reasonably congruent. Research has been undertaken in this area and a recent BMA report has summarised some of the results: "Studies have shown that relatives' perceptions of the patient's likely views often differ substantially from the patient's own wishes."<sup>46</sup>

It may also be noted that absolute quality of life judgements may, in certain circumstances, function as a mechanism of denial so that situations which the observer/decision-maker *themselves* find intolerable, are not permitted to continue. An example of such denial is found in the response of a medical witness in the Karen Quinlan case,<sup>47</sup> to the suggestion that Karen might be conscious: "... it's theoretically possible, in terms of animal experiments. ... but I don't know how you're going to find out. I think it's one of the most horrendous things you can imagine."<sup>48</sup>

### Section 3: The concept of best interests.

This Section is divided into two parts. The first examines the concept of 'best interests' and shows its dependence on that of 'quality of life'; the second considers whether, in the *Ward* and *Bland* cases, the term 'best interests' implies an 'absolute' or an 'incremental quality of life' judgement.

#### 'Best interests' and 'quality of life' judgements

The term best interests is commonly used in discussing the medical treatment options for children and incompetent adults. Speaking of the usefulness of the term, a BMA report is less than fulsome in its praise:

"Best interests" presents an apparently reassuring standard by which decisions should be made but can be interpreted in many ways. ... In the past, "best interests" were often seen as synonymous with the most positive clinical outcome. Prolongation of life at almost any cost was seen to be in the patient's interests. ... The extent to which this view has disappeared is exemplified by the lengthy ethical debate which occurred in the Lords during the Bland case. This made clear that, in some circumstances, prolongation of life can be perceived as a harm and potentially as an assault. ... The Law Commission's analysis of "best interests" mentions the importance of taking into account the known wishes of the patient and clearly these must figure in any assessment. Frequently, however, the former wishes or values are unknown and relatives' recollections may be unreliable and so more objective standards must be considered.<sup>49</sup>

What are these "more objective standards"? To say to a patient's medical carers that the criterion that they must use in making treatment decisions for that patient is the patient's best interests, is to place *two* obligations on them which must be disentangled; these two obligations are:

- (i) The carers must look *only* to that patient's interest when making their decision. This means that the interests of the medical carers or of other patients (as manifested through scarcity of resources) or the interests of the patient's family (in so far as these do not - as they seldom will - fully coincide with the patient's interests)

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<sup>46</sup> BMA, *Withholding and Withdrawing Life-prolonging Medical Treatment: Guidance for decision making* (1999), Part 3C.18.3. See also an Irish Times report (4.2.1998) of an American study which found only a modest correlation between health values and quality of life; a high correlation had usually been assumed. The study had questioned elderly American patients and found that, given the choice, they preferred to live as long as possible in the state of health they were actually in, rather than to live a shorter life but in better health.

<sup>47</sup> Karen Quinlan's case was the first case involving PVS to come before the US courts. Her breathing had been sustained by a respirator and the court application was for permission to remove the respirator. The court permitted this; however, on its removal, Karen Quinlan did not die but continued to breath unaided and she survived for a further 10 years. The case was decided in 1976 and is reported as *In the Matter of Karen Quinlan, An Alleged Incompetent*, Supreme Court of New Jersey 355A 2d 647.

<sup>48</sup> Chris Borthwick "The Proof of the Vegetable: a Commentary on Ethical Futility" (1995) 4 *Journal of Medical Ethics* 205 at 208.

<sup>49</sup> BMA (1998) at p.11.

must be disregarded.<sup>50</sup>

- (ii) Given then that only the patient's interests are to be considered, the medical carers must act only in his *best* interests.

How is a decision to be made between two conflicting courses of action both of which, it is contended, are in the patients *best* interests? It was to resolve this very question that the concept of quality of life was devised. Thus, an analysis of the concept of 'best interests' leads to the concept of 'quality of life'; and thus the latter is the more fundamental. There is, however, no reason why a best interests judgement must be an absolute quality of life judgement; a best interests judgement may well be an incremental quality of life judgement though - as is argued in the following part - 'best interests' was used in the *Ward* and *Bland* cases in the sense of an absolute quality of life judgement.

As will also be seen in the following part, some judges in the *Bland* case, whilst accepting the best interests test, did not accept that the concept of quality of life could also be used. The reasons for this apparent contradiction are to do with a confusion between incremental quality of life and absolute quality of life; however, it is worth pointing out at this stage that much of the appeal of the concept of 'best interests' is due to its vague definition; to its being 'all things to all men'; as such there is a danger that it may function as an umbrella term providing shelter to other, unacknowledged, interests; this is especially so if denial is operative.<sup>51</sup>

#### 'Best interests' as used in the *Ward* and *Bland* judgements.

Two events happened to the *Ward* and to Tony *Bland* subsequent to the decision to withdraw ANH; the tube feeding was discontinued and they died. These events were intimately connected, so intimately connected that it may seem pedantic to ask which of the two events was in mind when it was decreed to be in each of their best interests that the tube feeding be discontinued; however, if honesty and clarity be the goal then it is important that the question be at least addressed.

Reliance is often placed on the distinction between direct and indirect intention (and the related doctrine of 'double-effect') in the analysis of such questions, though many regard the double-effect argument as pure sophistry, nothing other than an intellectual device to permit the avoidance of responsibility.<sup>52</sup> I suggest that a test proposed by R. A. Duff<sup>53</sup> in conjunction with the absolute/incremental quality of life distinction and a willingness to indulge in a simple thought experiment can clarify the meaning of 'best interests' as used in the *Ward* and *Bland* cases and can also permit the traditional double-effect analysis a further level of elucidation.

The thought experiment requires one to imagine that the consequences of an action - which in reality are closely intertwined - are not necessarily connected; and in this imagined scenario, to pose Duff's question as to which of the (now separated) consequences would be the criterion of success.

As an example, consider a woman with an ectopic pregnancy; the current medical treatment is such that the procedure undertaken to protect the life of the mother necessarily results in the death of the foetus. A traditional

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<sup>50</sup> A recent BMA report suggests that this requirement is not always honoured: "It is obvious, however, that money spent caring for irreversibly and severely brain-damaged patients is money which cannot be used to treat other patients. This is an issue which needs to be acknowledged and addressed on a national scale as part of the debate on rationing and prioritising of resources. The BMA is concerned that, in reality, cost factors probably have a disproportionate influence on decision making for this very vulnerable patient group and is also concerned that the lack of a clear societal consensus on this most vexed area may unfairly leave doctors open to criticism." (BMA, *Withholding and Withdrawing Life-prolonging Medical Treatment: Guidance for decision making*, (1999), 3C.18.5)

<sup>51</sup> Both Ernest Becker and Elisabeth Kübler-Ross have written extensively on the prevalence of the 'denial of death' amongst medical professionals.

<sup>52</sup> The BMA has acknowledged the existence of such criticism: "The use of a 'double effect' justification has frequently been criticized and the BMA would welcome views about whether it should or could be replaced." (BMA (1998) at p.7).

<sup>53</sup> The crucial question to be posed is "What is the criterion of success?", the answer to this question identifies the goal of the original procedure. (See footnote 30.)

double-effect analysis is that the killing of the foetus, though foreseen as a necessary consequence, was not the intended consequence of the procedure. A critic of the double-effect analysis will argue that since the death of the foetus was a necessary consequence, it was therefore intended and to suggest otherwise is disingenuous. Imagine, however, a medical advance which permitted the doctor to save the life of the mother without losing the life of the foetus. By posing the question as to whether the surgeon would use the current method or the imagined method, the true goal of the procedure can be quickly identified. The criterion of success in such a case is clearly the saving of the life of the mother and not the killing of the foetus; the saving of the life of the mother is the intended consequence, the killing of the foetus is not.

Now apply the same reasoning to the withdrawal of tube feeding from a PVS patient. Imagine that a new procedure has been invented whereby a patch placed on the arm of a patient allows their nutrition to be absorbed painlessly and effortlessly through the skin. Would such a patch have been used in the *Ward* and *Bland* cases? To do so would permit the tube feeding to be discontinued and the patient to live.

It is certainly true that in the *Ward* case the discomfort which the tube feeding caused was alluded to in many of the judgements; the withdrawal of tube feeding would have been justified on such grounds and the ensuing death recognised as an inevitable but unwanted side-effect. Such a judgement is eminently defensible and would have been an incremental quality of life judgement; the fact that the patient would be in a less troubled state after that tube was removed, amply vindicates the procedure. But such was not the situation in the *Bland* case simply because none of the judges believed that Tony Bland could feel pain; in fact, as subsequently emerged, the tube was not in fact disconnected but was left in place in case it was necessary to administer medication.<sup>54</sup> Thus, Tony Bland had no better quality of life immediately after the cessation of tube feeding than before, hence no incremental quality of life judgement was involved. Imagine now the nutrition patch of which we spoke earlier, being introduced into the debate; would it be seized on as the obvious solution? When O'Flaherty J., stated: "The ward may be alive but she has no life at all. ... the quality of the ward's life was never in issue; she is not living a life in any meaningful sense."<sup>55</sup> Would the nutrition patch have allayed his concerns? The answer is surely an obvious and emphatic no. This implies that though in the *Ward* case there may have been incremental quality of life grounds for the withdraw of ANH, these were not primary.

Thus, recasting the 'best interests' analysis which was used in the *Ward* and *Bland* cases, into the terminology of 'incremental/absolute quality of life' brings a degree of transparency to the underlying structure of the judgements and it becomes clear that the quality of life analysis implicit in these cases was primarily one based on absolute quality of life judgements.<sup>56</sup>

#### Section 4: Conclusions.

This article has argued that:

- (i) two meanings of the term quality of life can be distinguished: 'incremental quality of life' (a measure of the change in quality of life due to a proposed intervention) and 'absolute quality of life' (a measure of the totality of quality of life).

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<sup>54</sup> This emerged in a radio interview given by Dr. Howe who was the neurologist in charge of Tony Bland. (RTE Radio 1, 26.5.1999).

<sup>55</sup> The *Ward* case at p.432.

<sup>56</sup> It is necessary to enter one proviso to this analysis: in the *Bland* case, Lord Mustill argued that the judgement to withdraw ANH must be the result of a balancing of the conflicting interests of the patient and not the result of a judgement as to the 'quality of life' of the patient. To pursue this perspective in tandem with a 'best interests' analysis required that Lord Mustill adopt a novel and closely argued approach: he suggests that Tony Bland has no interests of any kind. When ANH was initially commenced Tony Bland had interests - as there then was the expectation of recovery - and the giving of ANH was then in his best interests. In order to be lawful there is the requirement that such medical intervention be in the patient's best interests; thus the commencement of ANH was lawful. Now, in so far as he has no interests - and *a fortiori* no best interests - to continue with the treatment is necessarily unlawful. Hence it must cease.

- (ii) incremental quality of life judgements do not presume an ability to make absolute quality of life judgements.
- (iii) absolute quality of life judgements should be avoided because they are unreliable and because they conflict with accepted norms of equality; no such objections were made against the use of incremental quality of life judgements.
- (iv) the concept of 'best interests' is dependant on that of 'quality of life'; and that best interests judgements as used in the *Ward* and *Bland* cases were primarily absolute quality of life judgements; the deaths of the Ward and of Tony Bland being not only the intended consequences but the very goal of the withdrawal of ANH.

A statement by Lord Goff in the *Bland* case brings the questions discussed in the article into sharp focus: having noted that the question before the court can sometimes be put in 'striking or emotional terms, which can be misleading', he continued:

The question is not whether the doctor should take a course which will kill his patient, or even take a course which has the effect of accelerating his death. The question is whether the doctor should or should not continue to provide his patient with medical treatment or care which, if continued, will prolong his patient's life. ... And then it is asked: can it be in the best interests of the patient that a doctor should be able to switch the life support system off, when this will inevitably result in the patient's death? Such an approach has rightly been criticised as misleading, ... This is because the question is not whether it is in the best interests of the patient that he should die. The question is whether it is in the best interests of the patient that his life should be prolonged by the continuance of this form of medical treatment or care.<sup>57</sup>

Lord Goff was anxious to draw a distinction between saying on the one hand that

- 'the patient is better off dead' (which is an absolute quality of life judgement); and
- 'the patient is better off without ANH even though it is a necessary consequence of the withdrawal of life support that he will die' (which is an incremental quality of life judgement).

A distinction is indeed possible if the patient immediately after the withdrawal of ANH is in a less troubled state than whilst ANH was being administered. Such could be the case with a sentient patient particularly if being fed by a nasogastric tube which, unlike the gastrointestinal tube, causes considerable discomfort. But this is not relevant to the situation of Tony Bland as described in the judgements. Thus, although the distinction sought to be made by Lord Goff is valid, his use of the distinction is not. It is the proposed distinction between incremental, and absolute quality of life judgements that has enabled the doctrine of 'double-effect' to be more rigorously stated, and this 'misuse' to be clearly seen.

Such criticism of the *Ward* and *Bland* judgements may seem to be churlish in that the courts were not afforded the luxury of indulging in an abstract analysis of an hypothetical problem; they were faced with a situation of great human suffering which stood before them in all its complexity, insisting on an appropriate response.<sup>58</sup> Furthermore, there appears to be wide social agreement with the decision of the courts in both cases. Nonetheless, it is important that the judgements be critically examined, not because of the decision to withdraw ANH *per se*, but because of the grounds used as justification and especially the acceptance of absolute quality of life judgements as an appropriate tool on which to base decisions to withdraw life-sustaining treatment. Despite protestations to the contrary<sup>59</sup> the acceptance of an undifferentiated 'quality of life' or 'best interests' framework will, having received

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<sup>57</sup> The *Bland* case at p.868.

<sup>58</sup> "To continue the treatment is as much a decision as not to do so." (Denham, J., The *Ward* case at p.456).

<sup>59</sup> e.g. Hamilton C.J., : "... my ruling in this matter will be based on and relate only to the circumstances and rights of this particular ward." (The *Ward* case p.423).

judicial sanction, undoubtedly be applied to other problems,<sup>60</sup> such as infant disability and dementia,<sup>61</sup> which bear a superficial resemblance to PVS.<sup>62</sup> The 'quality of life' framework is altogether too crude an instrument for such analysis in that it conflates situations which should, for legal and ethical reasons, be clearly distinguished. Absolute quality of life judgements draw no clear boundary between the extremes of anencephaly and Down Syndrome nor between cases of PVS, near-PVS and dementia. Nor do they provide an adequate framework for medical decision-making in relation to the terminally ill.

In such cases the issue of death is like a spectre permeating the entire discussion yet never fully acknowledged; it is important that it be brought centre-stage and that the discussion be refocused on the *death* resulting from the non-treatment. It is the death of the patient that gives rise to the legal and ethical importance of the decision to withdraw life-sustaining medical treatment, and to the apparent paradox of justifying a medical decision, supposedly taken in the best interests of a patient, yet which foreseeably results in their demise.

It is necessary to return to fundamentals and to pose the question 'Is death an evil?'; the recognition that an unqualified answer cannot be given to this question creates space for the concept of 'a good death' to emerge. The concept of 'a good death' with the addition of the concept of 'personhood'<sup>63</sup>, allows an alternative theoretical framework to be constructed which permits the analysis of the legal and ethical problems posed by conditions such as PVS and anencephaly, to be more fine-grained than is possible with the concepts of 'best interests' or (undifferentiated) 'quality of life'. Furthermore it provides a more satisfactory basis for medical decision-making in relation to the terminally ill and the aged, than is possible by using the concept of 'quality of life'. Had the decisions in the *Bland* and *Ward* cases been formulated within such a framework then the decision to withdraw life-sustaining treatment could have been justified without the danger of occasioning a slippery slope; the elaboration of such a framework might, perhaps, be the subject of a future article.

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<sup>60</sup> Particularly in that the judgements in the *Ward* case - unlike in the *Bland* case - did not stipulate that ANH be not withdrawn in future cases without prior application to the court.

<sup>61</sup> The Tresch study on misdiagnosis expressed surprise at the high level of dementia amongst a test population of patients who had been previously diagnosed as PVS: "This large number of patients in a PVS in our study who were diagnosed as having end-stage dementia is surprising. Patients with dementia rarely develop the profound and complete loss of awareness characteristic of PVS, and it is important to distinguish between a PVS and the usual dementia state." (Donald Tresch *et al*, "Clinical Characteristics of Patients in the Persistent Vegetative State." (1991) 151 Archives of Internal Medicine, 930 at 932).

<sup>62</sup> The danger of PVS becoming a catch all term which could be used to refer to any prolonged state of minimal awareness where recovery was seen as unlikely, was noted by McQuillen: "In recent years, some researchers have emphasized the essentially clinical nature of the 'vegetative state' and have attempted to extend its limits to include the end stage of any chronic, progressive, neurodegenerative disorder at one end of life and to compare it with anencephaly at the other." (Michael P. McQuillen, "Can People Who Are Unconscious or in the 'Vegetative State' Perceive Pain?" (1991), 6. 4 Issues in Law & Medicine 373 at 375.) These perceptions would tend to be confirmed by the high rate of misdiagnosis of PVS which has been found by many research studies; e.g. Andrews found a misdiagnoses rate of 43%. (Keith Andrews *et al*. "Misdiagnosis of the vegetative state: retrospective study in a rehabilitation unit." (1996) 313 British Medical Journal, 13 at 13).

<sup>63</sup> The concept of 'personhood' permits a distinction to be drawn between, for example, cases of anencephaly and Down Syndrome, and between cases of PVS and dementia.