

End of Life Decisions: The Extent to Which Quality of Life Factors Should Affect Them

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Abstract

The significance of quality of life factors in end of life decisions cannot be overstressed. However, a plethora of case law shows that there are other factors which must be considered. The landmark cases of *W v M and Others*¹ and *Airedale N.H.S Trust v Bland*² indicate that autonomy and best interests of the patient must be given adequate consideration before making end of life decisions. The courts held that despite M's minimally conscious state, dying was not in her best interests. However, in *Bland* where he had been in a persistent vegetative state, it was held that it was lawful for treatment to be withdrawn. This article gives a critical assessment of the disparities in both decisions and, with the aid of other case law, examines the extent to which quality of life factors have influenced the decisions of the courts. Furthermore, it argues whether patient autonomy should override best interests and then concludes that quality of life factors should influence end of life decisions to the extent of the patient's autonomy or self-determination. In other words, quality of life factors must be considered but respect for patient autonomy should be paramount.

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¹ [2011] EWHC 2443 (Fam).

² [1993] AC 789 (HL).

Introduction

At the very core of human existence is the notion of life and death. Every living soul will die at some point. As ubiquitous and inevitable as this may seem, it is not surprising that a lot of people avoid the topic especially when death could be said to be distant. Death is feared for a plethora of reasons amongst which it signifies the end of one's existence, we bid farewell to our loved ones and everything we hold dear. Although it is impossible to alter the course of nature, the world of medicine has somehow managed to prolong lives artificially thanks to technological advancement. This has led to numerous ethical issues arising from making end of life decisions. For the purposes of this article, focus will be on people with disorders of consciousness (DOC), who lack capacity such as coma, permanent or persistent vegetative state (PVS) and the subsequently introduced minimally conscious state (MCS). End of life decisions include, but are not limited to, how one chooses to die, when to die, who should make the decision, whether or not life-saving treatment and medical support should be continued or withdrawn and the factors to be considered in making the decision.

Sanctity of Life vs Quality of Life

The concept of the sanctity of life stems from the fact that life is precious and ought to be preserved at all costs. The source of this notion remains unknown and unclear as there is a wide misconception that it is nothing but a strict prohibition on euthanasia and physician-assisted suicide.³ The concept has a religious undertone of life belonging to deity that should therefore not be deliberately taken. The majority of religions practised today recognise the principle of sanctity of life. Orthodox

³ Heike Baranzke, "Sanctity-of-Life" – A Bioethical Principle for a Right to Life? (2012) 15 Ethical Theory and Moral Practice 295.

KENT STUDENT LAW REVIEW Volume 3 2017

Christians follow the commandment in the Bible which says “thou shall not kill.”⁴ Muslims believe that life is from Allah and only He can determine when a person is to die. Buddhists are not explicit on their perception of voluntary and non-voluntary euthanasia but they are clearly against involuntary euthanasia.⁵ The principle is also supported by people with no religious references, who just believe that life is intrinsically valuable, and nature should be allowed to take its course in end of life decisions. Despite their strict adherence to sanctity of life, most religions recognise the doctrine of double effect i.e. they understand that in some cases, death could be a side effect of a good act such as alleviating pain and suffering.⁶ It could therefore be argued that the lack of clarity on their positions proves that some religious opinions are a consensus subject to change.

If life is indeed intrinsically valuable regardless of one’s state, does that make the sanctity of life principle an absolute right by itself? What then happens in a situation where life is not worthwhile at all? Should this principle still stand when quality of life is low? The concept of quality of life holds that some lives are not worth living and that it is therefore right to end them.⁷ Peter Singer, a proponent of the utilitarian approach, opines that not all lives are worth living, some are of more value than others. Patients who have lost consciousness for instance and are unable to relate with others are not ‘living.’⁸ According to Maslow’s hierarchy of needs, our basic human needs from highest to lowest are self-actualization, esteem, love, safety and physiological needs i.e. the requirements for survival.⁹ Terminally ill patients,

⁴ Exodus 20:13.

⁵ Roy W Perrett, ‘Buddhism, Euthanasia and the Sanctity of Life’ (1996) 22 J Med Ethics 309.

⁶ *ibid.*

⁷ Jonathan Herring, *medical law and ethics* (6th edn, OUP 2016) 537.

⁸ Peter May, ‘Life after God?- The Ethics of Peter Singer’ <<http://www.bethinking.org/morality/life-after-god-the-ethics-of-peter-singer>> accessed 5 December 2016.

⁹ Avneet Kaur, ‘Maslow’s Need Hierarchy Theory: Applications and Criticisms’ (2013) 3 Global Journal of Management and Business Studies 1061.

especially those with disorders of consciousness, clearly have a low quality of life based on this theory. They are usually strapped to ventilators, have to undergo artificial nutrition and hydration, have no personal freedom, and in most cases they are unable to communicate. Despite these facts, supporters of sanctity of life argue that being alive albeit in a moribund state is better than no life at all. The courts also recognise the principle of sanctity of life but agree it is not always binding. As stated by Lord Goff in *Bland*, ‘..but this principle fundamental as it is, it is not absolute.’¹⁰ The contentious decision in *W v M* is a major reference point for the quality and sanctity of life debate.

In *W v M*,¹¹ M suffered viral encephalitis with irreparable brain damage which rendered her in what initially seemed to be a permanent vegetative state. However, it was subsequently confirmed that she was in fact minimally conscious, a state above the vegetative state. The applicant, M’s mother sought a declaration from the court that M lacked capacity to make decisions on future treatment and a further declaration that the life-sustaining treatment and medical support including Artificial Nutrition and Hydration (ANH) could legally be removed. The substantive issue before the court was whether it was in M’s best interests for life-sustaining treatment, including ANH, to be withdrawn or withheld. Lord Baker J who was the presiding judge recognised her low quality of life but found preserving her life to be in her best interests.¹² He held that in the absence of a formal advance direction, the issue had to be determined by the best interests test. He heard evidence of her initial autonomous wishes when she had capacity but he refused the application to withdraw ANH holding that:

¹⁰ *Airedale N.H.S. Trust v Bland* [1993] AC 789 (HL).

¹¹ *W v M and Others* [2011] EWHC 2443 (Fam).

¹² *ibid.*

KENT STUDENT LAW REVIEW Volume 3 2017

M does experience pain and discomfort ...however I find that she does have some positive experiences and importantly there is a reasonable prospect that those experiences can be extended by a planned programme of increased simulation.¹³

Lord Baker J's balance sheet approach weighs all the benefits and burdens of a decision against each other before determining what is in a patient's best interests. The trend in the courts however mostly leans toward a 'very strong presumption' on the preservation of life.¹⁴ On one hand this approach was appropriate because life in itself is characterised by varying degrees of pleasure and pain. On the other hand, it is not without its faults; although M could feel pleasure and pain, the fact that she had a low quality of life was uncontentious. If she did in fact feel those emotions, which was paramount between pleasure and pain? Neither the assessment tools nor the Judge could determine this and therefore Lord Baker J erred in assessing the situation that way. His approach will only give a precise answer where the patient's clinical condition and quality of life are either 'demonstrably satisfactory or overwhelmingly burdensome.'¹⁵ In my opinion, good quality of life transcends being able to appreciate the sun and some pleasures. There is a dire need for social interaction and personal freedom in every human being and being in a minimally conscious state falls below that standard. Furthermore, there was enough evidence to show that M would have detested being in such deplorable state. Yet, there was no evidence of Bland's previous wishes but treatment was withdrawn anyway.

¹³ *W v M and Others* [2012] 1 WLR 1653 [8].

¹⁴ *ibid* [7].

¹⁵ Alexandra Mullock, 'Best Interests and the Sanctity of Life After *W v M*' (2012) 39 *J Med Ethics* 553.

KENT STUDENT LAW REVIEW Volume 3 2017

In *Bland*, 17-year-old Anthony Bland was diagnosed as suffering from PVS as a result of his injuries following the disaster at the Hillsborough Football Stadium. He had been in a coma for three years and both his family and medical team sought a declaration that it was lawful to withdraw treatment and ANH. The courts established that life sustaining treatment had ceased to be in his best interests and a declaration was granted.¹⁶ This decision raises a number of ethico-legal issues on euthanasia and assisted suicide, but this paper will only address the factors considered in making the decision to grant a declaration. As is the case with MCS patients, those suffering from PVS are technically still alive as they are not immobile and retain some cranial nerve and spinal reflexes. Most importantly they are not brain dead.¹⁷ Lord Hoffman described Bland's life as being below that of the 'most pitifully handicapped.'¹⁸ There was an interplay between best interests and quality of life in deciding this case. Lord Keith emphasised the unbinding nature of the sanctity of life principle and Lord Goff explained the importance of differentiating situations where prolonging life is not in the patient's best interests due to the illegality of procedure and situations where life sustaining treatment is not in the patient's best interests because it is futile as in *Bland*.¹⁹

Lord Mustill's persuasive argument was that neither termination of life nor continuation of treatment was in Bland's best interests because death was inevitable and the doctor no longer had a duty to prolong life.²⁰ His relatives also had no evidence of his precedent autonomous wishes which is understandable considering death and dying are not popular topics of discussion among adolescents.²¹ However

¹⁶ *Airedale N.H.S. Trust v Bland* [1993] AC 789 (HL).

¹⁷ Jonathan Herring, *Medical Law and Ethics* (6th edn, OUP 2016) 519.

¹⁸ *Airedale N.H.S. Trust v Bland* [1993] AC 789 (HL).

¹⁹ *ibid.*

²⁰ *ibid.*

²¹ *ibid.*

his father was certain his son would not want to be left in that state. Singer explains that when a patient becomes irreversibly unconscious, life stops being of benefit.²² He also suggests that we go back to the traditional definition of death being the seizure of circulation of blood instead of brain stem death.²³ I disagree with this proposition on the basis that patients who are not brain stem dead are still alive and may enjoy some benefits such as some level of environmental awareness and a chance for recovery where possible.

The decisions in *Bland* and *W v M* raise the question of whether a distinction should in fact be made between PVS and MCS. In distinguishing M from PVS patients, she was said to be “recognisably alive in a way that a patient in the vegetative state is not.”²⁴ Diagnosis of the MCS is not as straightforward as PVS owing to the varying degree of sensation and there is evidence of a potential increase in the rate of erroneous diagnosis of patients with DOC.²⁵ However, patients in both categories are so severely impaired that they are unable to carry out daily living activities (low quality of life).²⁶ Mullock in his commentary on *W v M* explains that there were other cases before *Bland* where the patients were above the permanent vegetative state but treatment was withdrawn anyway.²⁷ He cites *Frenchchay HealthCare Trust v S*²⁸ and *Re H (Adult: Incompetent)*²⁹ as examples.

These cases indicate the attitude of the courts toward people presumed to be PVS patients and Lord Baker’s dictum in *W v M* concerning the courts’ proclivity

²² Peter Singer, ‘Presidential Address: Is the Sanctity of Life Ethic Terminally Ill?’ (1995) 9 *Bioethics* 327.

²³ *ibid.*

²⁴ *W v M and Others* [2011] EWHC 2443 (Fam), [2011] 1 WLR 1653 [221].

²⁵ Caroline Schnakers et al, ‘Diagnostic Accuracy of the Vegetative and Minimally Conscious State: Clinical Consensus versus Standardized Neurobehavioral Assessment’ (2009) 9 *BMC Neurology* 1471.

²⁶ Ronald E Cranford, ‘What is a Minimally Conscious State?’ (2002) 176 *West J Med* 129.

²⁷ Alexandra Mullock, ‘Deciding the Fate of a Minimally Conscious Patient: An Unsatisfactory Balancing Act? *W v M and Others* [2011] EWHC 2443’ (2012) 20 *Med L Rev* 460.

²⁸ [1994] 1 WLR 601.

²⁹ [1998] 2 FLR 36 (Fam).

toward granting the requests of PVS patients seeking termination of treatment corroborates this.³⁰ PVS patients seeking termination of treatment garner support from the courts but in M's case, the need to prolong life suddenly became prevalent. This inconsistency is evidence of the court's bias towards PVS patients. This bias is also present in the European Court of Human Rights as seen in *Lambert v France*.³¹ A possible counter argument is that the courts see MCS cases as more hopeful since recovery is not impossible. However, in severe cases such as M's, recovery is rather implausible.

Sheather makes a distinction between both categories based on the definitions of personal and biological deaths.³² According to him, MCS patients are biologically alive but personally dead due to the absence of their cognitive and psychological capacities while PVS patients are dead on both counts.³³ This distinction is grounded on technicalities with no substantial evidence. Being alive personally and biologically is the essence of living; one without the other equates to low quality of life. Ashwal and Cranford's claim that the MCS is in fact worse than the PVS stretches the argument beyond the need for a distinction.³⁴ I agree to a large extent because a MCS patient could be in a more distressed state due to the intermittent nature of consciousness and inability to communicate.³⁵ It is essentially being confined to the prison of one's body and being aware. PVS patients on the other hand are completely oblivious, have little to no chance of recovery and are

³⁰ *ibid* (n 24) [35].

³¹ (2016) 62 EHRR 2.

³² Julian C Sheather, 'Should We Respect Precedent Autonomy in Life-Sustaining Treatment Decisions?' (2013) 39 J Med Ethics 547.

³³ *ibid*.

³⁴ S Ashwal and R Cranford, 'The Minimally Conscious State in Children' (2002) 9 Seminars in Pediatric Neurology 19.

³⁵ Dominic Wilkinson and Julian Savulescu, 'Is it Better to Be Minimally Conscious than Vegetative?' (2012) 39 J Med Ethics 557.

KENT STUDENT LAW REVIEW Volume 3 2017

“beyond suffering.”³⁶ Therefore, a distinction should not have been made between *Bland* and *W v M*; treatment was futile in both cases.

Supporters of the principle of sanctity of life emphasize the importance of palliative care.³⁷ I agree with the logic behind this in that patients could be so well taken care of that there would be no desire for assisted suicide. For instance, *Purdy*³⁸ and *Daniel James*³⁹ may not have requested assisted suicide if there had been better palliative care. This argument can however be refuted by the inability of palliative care to eradicate the helpless and mental anguish that patients with DOC feel.⁴⁰ The idea behind death with dignity for most is dying without being a burden to their loved ones and the best palliative care may not be able to allay this concern. Hence, respect for autonomy should be paramount.

Neither the sanctity nor quality of life principle is sufficient to justify end of life decisions. Sanctity of life is limited in scope and therefore should not be imposed on others. Furthermore, it can be displaced by the doctrines of double effect and necessity. Patients with disorders of consciousness with no hope of recovery are as good as dead and dying is not always necessarily bad. Sometimes ending a patient's life could be in their best interests as seen in *Bland*. Lady Hale in *Aintree University Hospital v James*⁴¹ with the application of *Bland* suggests that it is wrong to ask whether it was in the patient's best interests to die. Instead the question to be asked is whether it is in the patient's best interests to receive treatment.⁴² Doing this shifts the focus from the patient's death to the futility or non-futility of treatment and as Lord

³⁶ L Syd M Johnson, 'The Right to Die in a Minimally Conscious State' (2010) 37 J med Ethics 175.

³⁷ Maaïke Hermsen and ten Have Henk, 'Euthanasia in Palliative Care Journals' (2002) 23 Journal of Pain and Symptom Management 517.

³⁸ *R (on the application of Purdy) v Director of Public Prosecutions* [2009] UKHL 45.

³⁹ Robert Booth, 'He Wasn't Prepared for a Second-Class Life: Why Injured Rugby Star Went to Switzerland to Die' *The Guardian* (London, 18 October 2008) < <https://www.theguardian.com/uk/2008/oct/18/11> > accessed 6 December 2016.

⁴⁰ Emily Jackson, *Medical Law Text, Cases and Materials* (4th edn OUP 2016) 960.

⁴¹ [2013] UKSC 67.

⁴² *ibid* [21].

KENT STUDENT LAW REVIEW Volume 3 2017

Baker J states concerning sanctity in *Gloucestershire Clinical Commissioning Group v AB*,⁴³ the principle 'does not impose an obligation to provide treatment where life is futile.'⁴⁴

A major shortcoming of the quality of life principle is its vagueness. It raises some unresolvable questions such as, how much suffering and pain is too much? At what stage should life be terminated? Also, lifestyles differ, hence what may be perceived as unbearable to one person may be manageable by another. Therefore, merely assessing what is perceived to be the quality of life is not sufficient. When dealing with relative issues such as how a person wishes to die, it is important for one's individuality to be taken into consideration. Consider the kind of life the patient has led. What would they have wanted? Daniel James was only paralysed but went to Dignitas anyway because he could not bear living that way.⁴⁵ Chan and Tipoe argue that denying a patient in a MCS life-sustaining treatment on grounds of low quality of life 'represents grave discrimination against disabled persons.'⁴⁶ This logic is fundamentally flawed because minimal consciousness is a severe form of disability and categorising all disabled people into one class is the actual discrimination. Disabled people are able to lead normal and healthy lives and their quality of life may not be necessarily low. This is however subject to an individual's perception of a good quality of life. With MCS patients, quality of life factors may or not lead to the termination of treatment. It is a question of whether the benefits of being kept alive outweigh the burden.⁴⁷

⁴³ [2014] EWCOP 49.

⁴⁴ *ibid* [19].

⁴⁵ *ibid* (no 39).

⁴⁶ Tak Kwong Chan and George Lim Tipoe, 'Should We Continue Treatment for M? The Benefits of Living' (2014) 40 J Med Ethics 131.

⁴⁷ Dominic Wilkinson and Julian Savulescu, 'Is it Better to Be Minimally Conscious than Vegetative?' (2012) 39 J Med Ethics 557.

Should Best Interests Override Patient Autonomy?

As stated by Lord Mustill in *Bland*, doctors must comply with a competent adult's refusal of life-sustaining medical treatment.⁴⁸ The Mental Capacity Act 2005 requires doctors to comply with any applicable advance decision on refusal of life-sustaining treatment.⁴⁹ In the absence of this, actions taken on behalf of patients who lack capacity must be done in their best interests.⁵⁰ Concerning life-sustaining treatment, it provides that there must be no desire to bring about death.⁵¹ Medical law cases are dealt with based on the merits of each case therefore it would be unreasonable to suggest that best interests should always override patient autonomy or vice versa. However, this paper argues that there are instances where one could be more prevalent than the other. Patient autonomy should override best interests where there is evidence of precedent autonomous wishes of the patient as seen in *W v M*. The law recognises the need to take into account the patient's previous wishes in determining their best interests but the weight to be attached to such wishes depends on the facts of each case.

Arguments for the continuation of M's treatment based on the best interests approach include a better chance of recovery than PVS patients. Recovery is not impossible in a MCS according to the research carried out by Bruno and others.⁵² However as already established, this was not the case in M's situation. Another reason given is that MCS patients enjoy the benefits of some environmental awareness and in M's case she was responsive.⁵³ This argument cuts both ways;

⁴⁸ *Bland* (no 18).

⁴⁹ Mental Capacity Act 2005, s 24.

⁵⁰ *ibid* s 4.

⁵¹ *ibid* s 4(5).

⁵² M A Bruno *et al*, 'Prognosis of Patients with Altered State of Consciousness' in Caroline Schnakers and Steven Laureys (eds) *Coma and Disorders of Consciousness* (Springer London 2012).

⁵³ Dominic Wilkinson and Julian Savulescu, 'Is it Better to be Minimally Conscious than Vegetative?' (2012)39 J Med Ethics 557.

KENT STUDENT LAW REVIEW Volume 3 2017

M's responses could have been indicative of either pleasure or pain, discomfort and distress.⁵⁴ Demertzi and others explain the difficulty in assessing the gravity of the pain and the level of awareness of minimally conscious patients in their European survey of medical and paramedical professionals.⁵⁵ This explains this paper's criticism of decisions made solely on the best interests approach. No one can really know how much pain a person is in except that person.

Furthermore, the prognosis of physicians and carers is not always reliable as their judgements may be clouded by their attachment and closeness to the patient. Therefore, in M the courts gave too much consideration to evidence from carers. It should be noted that the decision to allow a loved one to die is not whimsical. Therefore, one would imagine M's relatives were indeed genuine about M's presumed wishes. Evidence of what a patient would have wanted should be differentiated from wishes of third parties such as parents as seen in *Re A (A Child)*.⁵⁶ This is not a proposition for a blanket denial of life-sustaining treatment for MCS patients. The best interests test is case specific; therefore my argument is that courts should respect and obey precedent autonomous wishes of patients who lack capacity. M's case was at the extreme end of the spectrum and there was enough evidence to suggest that she would have wanted a more dignified death.

Best interests should override autonomy in the withdrawal or withholding of treatment in children. Parents are expected to make end of life decisions for their children, however where there is a disagreement on the appropriate line of action between parents and doctors, the courts intervene and such a child becomes a ward

⁵⁴ Rob Heywood, 'Withdrawal of Treatment from Minimally Conscious Patients' (2012) 7 Clinical Ethics 10.

⁵⁵ A Demertzi *et al*, 'Different Beliefs about Pain Perception in the Vegetative and Minimally Conscious States: A European Survey of Medical and Paramedical Professionals' (2009) 177 Progress in Brain Research 329.

⁵⁶ [2015] EWHC 443 (Fam).

KENT STUDENT LAW REVIEW Volume 3 2017

of the court. In *Re A (Conjoined Twins)*⁵⁷, the bone of contention was whether to separate the twins and enable only one of them survive or keep them conjoined which would result in their inevitable deaths.⁵⁸ The parents opted for the latter alternative based on their religious beliefs founded on the principle of sanctity of life. Mary's quality of life was considerably lower than Jodie's and from a medical standpoint, she had no chance of survival with or without separation. In lay terms, the courts had to choose the lesser of two evils.

The courts' paramount consideration was the best interests of the children with Lord Brooke establishing that the case satisfied all requirements for the application of the doctrine of necessity i.e. preserving Jodie's life would have a greater utilitarian value than that of Mary's.⁵⁹ They referred to other principles such as bioethics, Kantian theory, virtue ethics, utilitarian principle, non-maleficence amongst others. This indicates the onerous nature of end of life decisions. Although the children's best interests were irreconcilable, Lord Walker J's opinion which I agree with was that the surgery was in their best interests and that the operation would give Mary 'bodily integrity as a human being even in death.'⁶⁰ The operation was carried out and Jodie lives on till date. If the courts had obeyed the wishes of her parents, she would have been denied the life she now enjoys.⁶¹

Another case where the courts rightly chose best interests over parental autonomy was *Re A (A Child)*.⁶² In this case, the patient had been declared clinically dead following brain stem death. The parents objected to the turning off of

⁵⁷ [2001] 2 WLR 480.

⁵⁸ *ibid.*

⁵⁹ *Re A (Conjoined Twins)* [2001] 2 WLR 480.

⁶⁰ *ibid.*

⁶¹ Ollie Gillman, 'Separated Twin is Now Living a Full Life, Says Judge who Ordered the Operation that Killed her Conjoined Sister' *Daily Mail* (London 4 October 2014) < <http://www.dailymail.co.uk/news/article-2780371/Separated-twin-living-life-says-judge-ordered-operation-killed-conjoined-sister.html> > accessed 5 December 2016.

⁶² [2015] EWHC 443 (Fam).

KENT STUDENT LAW REVIEW Volume 3 2017

the ventilator based on religious beliefs. Coroner sought for a declaration to be granted jurisdiction over child's body. Declaration was granted.⁶³ This decision was obvious as there was really no quality of life to be considered. Therefore, the parents' insistence of continuation of treatment was futile. This paper is not suggesting a denial of the right of parents to make end of life decisions for their children. However, these two cases exemplify the difficulty in ascertaining objectiveness in parents. Religious sentiments ought to be respected but when dealing with life and death issues, other factors especially best interests must be given more consideration.

There is undoubtedly the question of whether this gives the courts too much power over another person's child. This could be true because the courts unarguably usurp the responsibility of the parents but they are also in a better position to determine what the best interests are. They are not emotionally involved, therefore they are more clear minded and objective. This position is not as clear cut in the case of post-mortem pregnancy where the mother has expressed her wishes not to be kept alive and the foetus is viable. The courts will have to weigh the competing interests of mother and foetus.⁶⁴ Personhood and other factors outside the scope of this paper are to be considered in determining the appropriate line of action. The limitation to the best interests test is the varying margin of interpretation of best interests. Responses given by MCS patients for instance may be interpreted narrowly as was done by Lord Baker in *M* or based on a wider consideration of issues.⁶⁵

⁶³ *ibid.*

⁶⁴ Alexis Gregorian, 'Post-Mortem Pregnancy: A Proposed Methodology for the Resolution of Conflicts over Whether a Brain Dead Pregnant Woman Should Be Maintained on Life-Sustaining Treatment' [2010] 19 *Annals of Health Law* 401.

⁶⁵ Rob Heywood, 'Withdrawal of Treatment from Minimally Conscious Patients' (2012) 7 *Clinical Ethics* 10.

KENT STUDENT LAW REVIEW Volume 3 2017

Moving beyond the argument of autonomy overriding best interests and vice versa, it should be noted that autonomy is not an absolute right. Dying is not an individual matter; it involves the family members as well as the healthcare providers, thereby limiting the autonomy of the patient. Physicians are trained not to readily give up on their patients and any form of response may be a glimmer of hope. Furthermore, a patient's previous wishes when there was capacity may have changed after capacity is lost. There is an emergence of new priorities; therefore Lord Baker's assessment of M's situation was not entirely wrong.⁶⁶ This limitation, although disguised as benevolent paternalism, is also present in the autonomy of competent patients as seen in the case of Mrs B.⁶⁷ Another limitation to autonomy is the need to seek declaration about proposed withdrawal and withholding of ANH from PVS and MCS patients according to the Practice Direction under the Court of Protection Rules 2007. It should however be noted that in MCS cases after *Aintree*,⁶⁸ in the absence of legally binding advance decisions, more weight has been given to family's views on what the patient would have wanted.⁶⁹

The Role of Advance Directives

The importance of terminally ill patients having advance decisions about treatment cannot be overemphasised because it is autonomous and legally binding. M's case would not have been so controversial and her autonomy would have been respected if she had it. However, there are limits to the application of advance decisions. They do not envisage all situations and there is usually no adequate consideration before decision is made. Therefore, they are not always reliable and hence, the need to

⁶⁶ Julian C Sheather, 'Should We Respect Precedent Autonomy in Life-Sustaining Treatment Decisions?' (2013) 39 J Med Ethics 547.

⁶⁷ *Re B (Adult Refusal of Medical Treatment)* [2002] 1 FLR 1090.

⁶⁸ *Aintree University Hospital v James* [2013] UKSC 67.

⁶⁹ Emily Jackson, *Medical Law Text, Cases and Materials* (4th edn OUP 2016) 1006.

respect patient autonomy. In lieu of this, I agree with Johnson's proposition that surrogate decision makers be appointed.⁷⁰

Conclusion

As asserted in this article, quality of life factors must be considered in end of life decisions but autonomy should be given more weight. The duty of the courts to prolong life should not override their legal obligation to respect autonomy.⁷¹ This is not suggesting that physicians blindly follow the wishes of the patient. They still have a duty to treat patients in their best interests. However, in cases where level of sensation is unascertainable such as the minimally conscious state, end of life decisions must be made upon respect for the patient's previous wishes. The courts should not have made a distinction between *W v M* and *Bland*; treatment was futile in both cases. As with everything in life, change is constant. Although life stops being of benefit, patients adapt and begin to enjoy whatever benefits are derivable from a disorder of consciousness. Therefore, a patient's previous wishes may change as a result of their current terminal situation and termination of life may not be the desired option.

Kassim, Alias *et al* state the need for healthcare providers to discover the personal, religious and spiritual beliefs of patients concerning end of life issues.⁷² This ensures collaborative decision making and less likelihood of misunderstanding and it also goes a long way in maintaining the doctor/patient relationship.⁷³ If a terminally ill patient *voluntarily* decides that the suffering and pain is too much and

⁷⁰ L Syd M Johnson, 'The Right to Die in a Minimally Conscious State' (2010) 37 J med Ethics 175.

⁷¹ Alexandra Mullock, 'Deciding the Fate of a Minimally Conscious Patient: An Unsatisfactory Balancing Act? *W v M* and Others [2011] EWHC 2443' (2012) 20 Med L Rev 460.

⁷² Jahn Kassim *et al*, 'Religious, Ethical and Legal Considerations in End-of-Life Issues: Fundamental Requisites for medical Decision Making' (2016) 55 Journal of Religion and Health 119.

⁷³ *ibid*.

KENT STUDENT LAW REVIEW Volume 3 2017

wish to end their life, it is not the right of the law or physician to decide otherwise. As established in this paper, neither quality of life nor sanctity of life considerations are sufficient to justify end of life decisions and according to Mullock:

the legal requirement to consider the past wishes and views of incompetent patients should not be seen as an opportunity for the judiciary to choose either autonomy or sanctity, but rather an obligation to respect autonomy.