

**THE GROWTH OF PATIENT AUTONOMY IN  
MODERN MEDICAL PRACTICE AND THE DEFINED  
LIMITATIONS UNDER THE *SHARĪ'AH***

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**ABSTRACT**

*The concept of patient autonomy or self-determination is one of the dominant ethos in modern medical practice. The demands by patients to be given respect, independence and dignity in medical decision making have been heeded and mirrored in many ethical codes and judicial decisions. The development of the law relating to informed consent, euthanasia, confidentiality, and reproduction issues have clearly reflected the reinforcement of patient autonomy in which patients' choices should be free from coercion and unwanted interference. Paternalistic infringement in these areas have been regarded as outmoded and are disfavoured, as respect for a patient's right to determine his own*

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*destiny is given precedence. The escalating medico-legal cases have further emphasised the salience of this concept in the provision of medical services. Nevertheless, while the importance of patient autonomy is duly recognised, the advancement of this concept is not without its limitations; it accordingly has to evolve within the perimeters of one's religious and cultural precepts. For Muslim patients, the right and ability to make their own choices and decisions about medical care and treatment must be within the defined limitations of the Shari'ah. The emphasis on individualism, personal gratification and the denial of faith in medical decision making is inconsistent with Islamic values. Therefore it is necessary that principles relating to the concept of patient autonomy be developed within the sphere of the Shari'ah, in order to ensure their coherence with the doctrinal requirements stipulated in Islam.*

**Keywords:** medical practice, autonomy, self-determination, medical paternalism, *shari'ah*, limitations

## **PERTUMBUHAN AUTONOMI PESAKIT DALAM AMALAN PERUBATAN MODEN DAN PENTAKRIFAN HAD DIBAWAH SHARĪ'AH**

### **ABSTRAK**

*Konsep autonomi pesakit atau penentuan nasib sendiri merupakan salah satu etos yang dominan di dalam amalan perubatan moden. Tuntutan para pesakit agar dihormati, diberi kebebasan dan layanan bermaruah dalam amalan perubatan telah diberi perhatian dan dicerminkan dalam kebanyakan kod etika dan keputusan kehakiman. Perkembangan undang-undang berkaitan izin bermaklumat, "euthanasia", kerahsiaan dan isu-isu reproduktif jelas mencerminkan pengukuhan autonomi pesakit, yang mana pilihan yang dibuat oleh pesakit perlu*

*bebas daripada paksaan dan gangguan yang tidak diingini. Pendekatan paternalistik di dalam perkara-perkara tersebut dianggap telah ketinggalan zaman dan keutamaan diberi kepada hak pesakit untuk menentukan nasibnya sendiri. Peningkatan di dalam kes-kes mediko-legal juga menunjukkan kepentingan konsep ini di dalam perkhidmatan perubatan. Namun begitu, walaupun kepentingan autonomi pesakit diakui sewajarnya, konsep ini tertakluk kepada beberapa batasan; ia haruslah berkembang mengikut sempadan konsep agama dan budaya seseorang. Bagi pesakit-pesakit yang beragama Islam, hak dan kemampuan untuk membuat pilihan dan keputusan tentang penjagaan dan rawatan perubatan perlu mematuhi batasan-batasan Shari'ah yang telah ditentukan. Penekanan terhadap individualisme, kepuasan peribadi dan penafian terhadap mana-mana kepercayaan di dalam membuat keputusan perubatan adalah bercanggah dengan nilai-nilai Islam. Oleh itu adalah perlu agar prinsip-prinsip autonomi pesakit dibangunkan mengikut batasan Shari'ah bagi memastikan kepaduannya dengan keperluan-keperluan doktrin yang telah ditetapkan dalam Islam.*

**Kata Kunci:** amalan perubatan, autonomi, penentuan nasib sendiri, paternalisme perubatan, *shari'ah*, had

## INTRODUCTION

Autonomy is considered by many as the most important bioethical principle in medical practice.<sup>1</sup> It is the fundamental right of the patient to conduct and manage his own affairs, including deciding what should be done with his body.<sup>2</sup> Particularly in medical decisions, patients' preferences are to be given pre-eminence since

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<sup>1</sup> Steinberg, A, "Medical ethics", in *Encyclopedia of Jewish Medical Ethics: A Compilation of Jewish Medical Law on All Topics of Medical Interest*, Vol. 1, Steinberg, A. and Rosner, F. (eds.), (Jerusalem: Feldheim Publishers, 2003), 389-404. at p.395.

<sup>2</sup> *Ibid.*

medical decisions reflect value judgments, and patients are therefore the best authority to decide their own values and goals rather than doctors.<sup>3</sup> The doctor-patient covenant is seriously breached if the doctor offers medical procedures that conflict with the patient's values.<sup>4</sup> As respect for autonomy or the right to self-determination becomes an important precept in ethical medical conduct, the doctor "may not restrict nor negate the free wishes of an individual with respect to his own body...[o]ne must facilitate any desired action acceptable to a person's own judgment and in accordance with his own choice."<sup>5</sup> Accordingly, to infringe a patient's autonomy is "to deprive him of one essential component of his own good"<sup>6</sup> and this violates the aim of medicine to act for the good of the patient.<sup>7</sup>

## THE CONCEPT OF PATIENT AUTONOMY AND SELF-DETERMINATION

Autonomy is synonymous with self-determination. Autonomy comes from the Greek terms *autos* (the ability to decide by oneself) and *nomos* (governance or the law to which one complies).<sup>8</sup> The crux of autonomy is thus, self-rule. An individual must be capable of determining his own life in accordance with his values, goals and beliefs. In health, it means a special form of personal liberty, where

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<sup>3</sup> Brett, A. S. and McCullough L. B., "Addressing requests by patients for non beneficial interventions" Vol. 307 (2) (2012), *JAMA*, 149-50 at p. 149; Baumgarten, E., "The concept of patient autonomy", Vol.2(3)(1999), Vol. 2, No. 3, *Medical Updates*, 1-6 at p. 2.

<sup>4</sup> Billings, J. A. and Krakauer, E. L., "On patient autonomy and physician responsibility in end-of-life care", *Arch Intern Med* 849-853, Vol. 171, No. 9 (2011): 850.

<sup>5</sup> *Supra*, n. 1 at p.13.

<sup>6</sup> Pellegrino, E. and Thomasma, D., (1987), "The conflict between autonomy and beneficence in medical ethics: proposal for a resolution", *J. Contemp. Health L. & Pol'y*, Vol. 3 (23) (1987) 23-46: 36, 50.

<sup>7</sup> *Ibid.*

<sup>8</sup> Puteri Nemie Jahn Kassim, *Law and ethics relating to the medical profession*, (Petaling Jaya: International Law Book Services, 2007), 6.

individuals are free to choose and implement their own decisions, free from deceit, duress, constraint and coercion. Therefore, autonomy can only occur in the absence of external control or pressure. A patient has a right to autonomous decision making and should not be overridden by the phrase “doctor knows best”. This has been propounded by Beauchamp and Childress, which has largely influenced scholarly analysis on the concept of autonomy in bioethics.<sup>9</sup> According to Beauchamp and Childress, apart from being voluntary and not subjected to any controlling influences or constraints from others, autonomous decisions are those which are made with substantial understanding upon being properly informed.<sup>10</sup> There is thus a duty on the part of the doctor to disclose medical information that is necessary for the patient to form an autonomous decision. However, an ethical dilemma exists when the patient’s choices conflict with what the doctor perceives to be in the patient’s best interests. Baumgarten points out that “the notion that patients have a moral claim to direct the course of their own medical care and to be given reasonably full information in order to make medical decisions is the most significant challenge of the bioethics movement to conventional medicine.”<sup>11</sup> Accordingly, in a variety of circumstances in medical practice, patient autonomy operates on a wide spectrum, “ranging from very high, where patients make all decisions, to very low, where they have minimal decision-making involvement.”<sup>12</sup>

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<sup>9</sup> See Beauchamp, T. L. and Childress, J. F., *Principles of Biomedical Ethics*. 5th ed., (Oxford: Oxford University Press, 2001), 57-103.

<sup>10</sup> *Ibid.*

<sup>11</sup> Baumgarten, *supra*, n. 3 at p. 1.

<sup>12</sup> Agarwal, A. and Murinson, B., “New dimensions in patient–physician interaction: values, autonomy, and medical information in the patient-centered clinical encounter”, *Rambam Maimonides Medical Journal*, Vol. 3(3) (2012) 1-11: 4.

## THE DECLINE OF MEDICAL PATERNALISM

Paternalism has been defined as “interference with a person’s liberty of action justified by reasons referring exclusively to welfare, good, happiness, needs, interests or values of the person being coerced.”<sup>13</sup> In the context of “medical paternalism”, the term refers to interference by the doctor with the patient’s freedom of action which is justified on the grounds of the patient’s best interest.<sup>14</sup> This concept stems from the idea that the patient is not and cannot be qualified to comprehend the technicalities of his own medical condition and that the medical attendant will do it for him, acting in the capacity of a benevolent parent. In the words of Steinberg, “paternalism is an approach in which the physician chooses the treatment for the patient because the physician’s professional knowledge, experience and objectivity best qualify him to judge the ideal treatment for the patient.”<sup>15</sup> Medical ethics, from the Hippocratic Oath onwards, has taken a thoroughly paternalistic position, emphasising on the patient’s well-being above any of his dignitarian interest. Paternalistic doctors hold firm to the principle that they should act to bring about maximum benefit for the patient. This is not a novel stand as it dates back to the undertaking of the Hippocratic Oath to apply “dietetic measures for the benefit of the sick according to my ability and judgment... [and] keep them from harm and injustice. Such undertaking is also echoed in the Declaration of Geneva by the words “the health of my patient will be my first consideration.”<sup>16</sup>

However, the last century has seen greater focus of patient autonomy with medical paternalism being pushed to the backseat. The move from paternalism to patient autonomy is clearly illustrated by Chin by comparing the 1847 and 1990 ethical codes of the

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<sup>13</sup> Weiss, G. B., “Paternalism modernised”, *Journal of Medical Ethics* Vol. 11(1985) 184-7: 184.

<sup>14</sup> *Ibid.*

<sup>15</sup> *Supra*, n. 1 at p. 19. A classic example of medical paternalism is withholding important information from the patient before a proposed treatment, fearing that disclosure may have an adverse effect on the patient or that he might refuse a potentially life-saving procedure.

<sup>16</sup> Brett, A. S. and McCullough L. B., “Addressing requests by patients for non beneficial interventions” Vol. 307 (2) (2012), *JAMA*, 149-50 at p. 149; Baumgarten, E., “The concept of patient autonomy”, Vol.2(3)(1999), Vol. 2, No. 3, *Medical Updates*, 1-6 at p. 2.

American Medical Association (AMA).<sup>17</sup> Section 6 of article II of the 1847 AMA ethical code entitled “Obligations of patients to their physicians” contains the following statement:

The obedience of a patient to the prescriptions of his physician should be prompt and implicit. He should never permit his own crude opinions as to their fitness, to influence his attention to them. A failure in one particular may render an otherwise judicious treatment dangerous, and even fatal.

The opinion issued by AMA in 1990 under “Fundamental Elements of the Patient-Physician Relationship” however, takes on a different standpoint on the matter. It reads:

The patient has the right to make decisions regarding the health care that is recommended by his or her physician. Accordingly, patients may accept or refuse any recommended medical treatment.

The strong deference to patient autonomy is attributable to several factors such as the emphasis on individualism and self-responsibility, and rapid technological advancements.<sup>18</sup> The emergence of sophisticated devices and treatment in medicine such as life-sustaining interventions for example, elicited a lot of ethical issues pertaining to the dying process, where patients’ values mattered the most. Further, the doctor-patient relationship began to take on a different dimension as patients gained easy access to medical information, resulting in decreased reliance on the doctor and the augmentation of medical awareness. The main argument against medical paternalism is that the doctor cannot and can never know enough about their patient’s values, wants, needs, interests, hopes and fears in order to make decisions for

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<sup>17</sup> Chin, J., “Doctor-patient relationship: from medical paternalism to enhanced autonomy” *Singapore Med J*, Vol. 43 (3)(2002) 153-155: 152.

<sup>18</sup> See da Rocha, A., “Back to basics in bioethics: reconciling patient autonomy with physician responsibility”, *Philosophy Compass* Vol. 4(1) (2009) 56-68: 58; *Supra*, n. 12 at pp. 2-8; Billings and Krakauer, *supra*, n. 4 at 850; Chin, *supra*, n. 17 at 152.

them.<sup>19</sup> For instance, before a patient is subjected to any treatment, patient autonomy requires that all the relevant information about his condition, possible modes of treatment coupled with their risks, benefit and side effects be made available to the patient. Medical paternalism, on the other hand, views that patients are generally incapable of understanding medical assessment of risks and benefit; as laymen, they lack medical training and the relevant experience and thus, patients cannot possibly be entrusted to make sound medical judgments.

## **THE GROWTH OF PATIENT AUTONOMY IN SELECTED AREAS IN MEDICAL PRACTICE**

### **i. Patient Autonomy in the Law on Informed Consent**

The growth of patient autonomy has been quite significant in the development of the law on informed consent. The doctrine of informed consent embodies the general principle that a person has a right to determine whether or not to undergo any medical procedure. A doctor should give the patient sufficient information for him to understand the nature of any proposed treatment, its implications and risks, and the consequences of not taking the treatment. In the light of that information, it is the patient who should decide what treatment, if any, he or she should undertake. The violation of the right to informed consent triggers a “claim” by a patient against a doctor for failure to give him sufficient information about a proposed medical treatment so as to provide him with the opportunity of making an “informed” or “rational” choice as to whether or not to undergo the treatment.”<sup>20</sup> The patient expects the law to give him dignity, respect, independence, autonomy, information and self-determination, and the development of the doctrine of informed consent clearly gives recognition to the patient’s right to self-determination. Meisel stated that the doctrine of informed consent “protects the patient’s right to determine his or her destiny in medical matters; it guards against overreaching on the part of the physician; it protects his physical

<sup>19</sup> *Supra*, n. 13 at p. 185.

<sup>20</sup> Robertson, G., “Informed consent to medical treatment” (Jan 1981) 97 LQR 102.

and psychic integrity and thus his privacy; and it compensates him both for affronts to his dignity and for the untoward consequences of medical care.”<sup>21</sup>

In developing the law on informed consent, the Malaysian courts have also attached more weight to a patient’s right to self-determination.<sup>22</sup> Prior to the decision of the Federal Court of Malaysia in *Foo Fio Na v Dr Soo Fook Mun & Anor*<sup>23</sup>, the court adopted a paternalistic approach in determining what information should be disclosed to the patient. The doctor was under a duty to make a “reasonable” disclosure of inherent risks in the proposed treatment. The question of what was “reasonable” in the particular circumstances was to be decided objectively. To determine what a doctor should disclose to his patient in relation to the inherent risks of the proposed treatment, evidence of medical experts was required and crucial. In other words, what a reasonable doctor would have done in similar circumstances would be determinative. This means that testimony by medical experts was the sole requisite. The need for a medical expert to testify suggests that how much information to be imparted to the patient is a matter of medical judgment. However, the decisions in *Foo Fio Na v Dr Soo Fook Mun & Anor*<sup>24</sup> and *Rogers v Whitaker*<sup>25</sup> reiterate that the standard to be observed by medical practitioners will no longer be determined solely or even primarily by medical practice as there will no longer be a conclusive force to medical opinion. Rather, it is for the courts to judge what standard should be expected from the medical profession taking into account not only medical opinion but other relevant factors surrounding the circumstances of the patient. The decision in *Rogers* emphasised that patients are entitled to make their own decisions about medical

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<sup>21</sup> Meisel, A., “The exceptions to the informed consent doctrine: striking a balance between competing values in medical decision-making”, *Wisc. Law Rev.*, (1979) 413: 414 - 415.

<sup>22</sup> The momentum of “patient autonomy triumphing over medical paternalism” has had enormous influence on the development of medical jurisprudence in disclosure of risks throughout the common law jurisdictions including England – *Chester v Afshar* [2004] 4 All ER 587, Canada – *Reibl v Hughes* [1980] 2 SCR 880 and Australia – *Rogers v Whitaker* (1992) 175 CLR 479.

<sup>23</sup> [2007] 1 MLJ 593.

<sup>24</sup> [2007] 1 MLJ 593.

<sup>25</sup> (1992) 109 ALR 625.

procedures and to be given sufficient information to make an informed choice. The High Court of Australia cautioned that the phrase “informed consent” commonly used by the American counterparts is “apt to mislead as it suggests a test of validity of the patient’s consent.... [and] consent is relevant to actions framed in trespass, not in negligence.”<sup>26</sup> The court further found that the expression “the right of self-determination” is also unsuitable “to cases where the issue is whether a person has agreed to the general surgical procedure or treatment, but is of little assistance in the balancing process that is involved in the determination of whether there has been a breach of duty.”<sup>27</sup> In determining what information is “material” for a given patient, the needs of each patient must be taken into account. The doctor must consider all that he or she knows about the patient, in order to decide, in the light of those circumstances, what risks the patient would be likely to consider significant. The High Court adopted the views of King C.J. in *F v R*<sup>28</sup>, and concurred that the question of how much information to be departed by a doctor cannot be determined by “any profession or group in the community”<sup>29</sup> but it should be determined upon consideration of complex factors, namely, “the nature of the matter to be disclosed; the nature of the treatment; the desire of the patient for information; the temperament and health of the patient; and the general surrounding circumstances.”<sup>30</sup> Thus, the High Court felt that opinions of medical witnesses should not be decisive at this point. In other words, it was for the courts, having regard to the “paramount consideration” that a person is entitled to make decisions about his own life, to set the appropriate standard of care. This point is considered the most significant aspect of the case as this means that the determination of the standard of care is a matter of judicial, not professional opinion. The judgment in *Rogers* was endorsed and followed by many recent informed cases in Malaysia such as *Abdul Ghafur bin Mohd Ibrahim v Pengarah, Hospital Kepala Batas & Anor*<sup>31</sup>, *Gurmit Kaur a/p Jaswant Singh v Tung Shin Hospital & Anor*<sup>32</sup> and *Sanmarkan a/l*

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<sup>26</sup> *Ibid* at p. 633.

<sup>27</sup> *Ibid*.

<sup>28</sup> (1983) 33 SASR 189.

<sup>29</sup> *Ibid* at p. 194.

<sup>30</sup> *Ibid* at pp. 192 - 193.

<sup>31</sup> [2010] 6 MLJ 181.

<sup>32</sup> [2012] 4 MLJ 260.

*Ganapathy & Anor (as administrators of the estate of Saradhamani a/p Doraisamy Gopal, the deceased) v Dato' Dr V Thuraisingham & Ors*<sup>33</sup>.

In the United Kingdom, the House of Lords ruling in *Chester v Afshar*<sup>34</sup> has shown a remarkable departure from the paternalistic and doctor-protective attitudes displayed in the renowned case of *Sidaway v Board Governors of Bethlem Royal Hospital and the Maudsley Hospital*<sup>35</sup> in which the court emphasised that “the law imposes the duty of care; but the standard of care is a matter of medical judgment.”<sup>36</sup> The case of *Chester v Afshar* involved complex issues of causation in finding the causal link between the breach of duty and the damage caused. As the operation was conducted with care and skill, the damage that resulted from the operation was not due to any breach of duty on the part of the doctor in handling the operation. Instead, the claim was made on the basis that the doctor had breached his duty in failing to warn the patient of the risks, which if properly warned, would have caused her to delay the treatment offered until she receives a second or third opinion<sup>37</sup>, and she would not have suffered the damage as yet. Relying on Lord Woolf’s observations in the case of *Pearce v United Bristol Healthcare NHS Trust*<sup>38</sup> that “if there is a significant risk which would affect the judgment of a reasonable patient, then in the normal course it is the responsibility of a doctor to inform the patient of that significant risk”<sup>39</sup>. Lord Steyn held that “in modern law medical paternalism no longer rules and a patient has a prima facie right to be informed by a surgeon of a small, but well established, risk of serious injury as a result of surgery.”<sup>40</sup> His Lordship went on to further state that “...a patient’s right to an appropriate warning from a surgeon when faced

<sup>33</sup> [2012] 3 MLJ 817.

<sup>34</sup> [2004] UKHL 41; [2005] 1 AC 134; [2004] 4 All ER 587; [2004] 3 WLR 927.

<sup>35</sup> [1985] 1 AC 871; [1985] 2 WLR 480; [1985] 1 All ER 643.

<sup>36</sup> [1985] 1 All ER 643 at p. 649.

<sup>37</sup> See Puteri Nemie Jahn Kassim, “*Chester v Afshar*: Loosening the grip on proving causation for failure to disclose risks in medical treatment”, *Current Law Journal*, Vol. 5 (2004): i - viii.

<sup>38</sup> (1998) 48 BMLR 118.

<sup>39</sup> *Ibid* at p. 124.

<sup>40</sup> [2004] 4 All ER 587 at p. 594.

with surgery ought normatively to be regarded as an important right which must be given effective protection whenever possible.<sup>41</sup>

The developments in these judicial cases reflect that patients nowadays, have grown increasingly forthright in asserting their rights against doctors who do not give credence to their rights of self-determination. Undeniably, “the days of paternalistic medicine are numbered. The days of unquestioning trust of the patient also appear numbered. The days of complete consent to anything a doctor cared to do appear numbered... doctors out of respect for themselves and their patients must increasingly face the obligation of securing informed consent from the patient for the kind of therapeutic treatment proposed...”<sup>42</sup> Further, the application of the law in modern health care setting has developed to offer a competent adult patient, once properly informed, the unassailable legal right to refuse medical treatment. Once the patient understands the nature, purpose of the proposed treatment, and the risks and likely prognosis involved in the decision to refuse or accept it, the patient achieves the required capacity to refuse the proposed treatment. In such circumstances, medical professionals should ensure that the advice given to the patient should be recorded together with written, unequivocal assurances from the patient that the refusal represents an informed decision. Lord Goff of Chieveley said in *Airedale NHS Trust v Bland*<sup>43</sup> stated that “it is established that the principle of self-determination requires that respect must be given to the wishes of the patient, so that, if an adult patient of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so . . . To this extent, the principle of the sanctity of human life must yield to the principle of self-determination: and, for present purposes perhaps more important, the doctor’s duty to act in the best interests of his patient must likewise be qualified.”<sup>44</sup> Further, Lord Donaldson in *Re T (An Adult: Medical Treatment)*<sup>45</sup> stated that “the patient’s right of choice is not limited to decisions

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<sup>41</sup> *Ibid.*

<sup>42</sup> Justice Michael Kirby, former President of the New South Wales Court of Appeal.

<sup>43</sup> [1993] 1 All ER 821; [1993] AC 789.

<sup>44</sup> [1993] 1 All ER 821 at p. 866.

<sup>45</sup> [1992] 2 FCR 861.

which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent.<sup>46</sup> Thus, it can be seen that the current trend amongst the courts have been to attach greater weight to the countervailing principle of a patient's self-determination as it is the right of every human being to make decisions which affect his own life and welfare and to decide on what risks he is willing to undertake. The right to determine what shall be done with one's own body is a basic human right firmly entrenched in and protected by the common law.<sup>47</sup> The concepts inherent in this right are the bedrock upon which the principles of self-determination<sup>48</sup> and individual autonomy are based and medical treatment carried out without the consent of an adult of sound mind amounts to unlawful touching or battery.<sup>49</sup>

## ii. Patient Autonomy in the Law of Euthanasia

The ethical principle of sanctity of life has always demanded that life is sacred and should be respected.<sup>50</sup> However, there are many

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<sup>46</sup> *Ibid* at p. 865.

<sup>47</sup> Justice Benjamin Cardozo, in *Schloendorff v Society of New York Hospital* 105 N.E. 92 (N.Y. 1914) stated that "every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages."

<sup>48</sup> Self-determination involves (1) the right to consent to treatment, to decide who shall treat and to choose the form of treatment; and as a corollary (2) the right to refuse consent.

<sup>49</sup> A battery takes place when there is non-consensual touching. In *Wilson v Pringle* [1986] 2 All ER 440, the Court of Appeal suggested that the touching must be "hostile" in order to constitute battery. The court was prepared to adopt a very wide view of hostility so as not to confine to acts of ill will but a little more than non-consensual touching. The reason for this is the need to eliminate actions in battery as a result of physical contact, which is generally acceptable in the ordinary conduct of everyday life. See further, *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1.

<sup>50</sup> The Declaration of Geneva mentioned the utmost respect for human life by stating that "all life is sacred on purely religious grounds, on the premise that all life comes from God." The complete text of the

occasions, in which the medical profession may face dilemmas particularly, in handling terminally ill patients. In such instances, patients may assert their autonomy by demanding that their lives be terminated to reduce their suffering or be allowed to die with decency and dignity.<sup>51</sup> Patients' values and spiritual beliefs are particularly significant at the end of life as it provides a sense of security and belonging to the patient by offering him a way to find meaning in dying as in life.<sup>52</sup> It has been constantly promoted in modern medical practice that clinical assessments on quality of life at this stage are not solely contingent on medical findings, but "should be based primarily on the patient's values, goals and beliefs"<sup>53</sup>, which makes respect for autonomy more pertinent in end-of-life care. Understanding patients' preferences, which are usually shaped by his values and beliefs, is the first step towards respecting patient autonomy at the end of life.<sup>54</sup> Conversely, a person's right to free choice forms the main contention of the proponents of euthanasia. It is suggested that if one has the right to exercise control over his life, one should also be entitled to choose when, where and how he should die.<sup>55</sup> Accordingly, a more

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declaration is available at <http://www.wma.net/en/30publications/10policies/g1/>.

<sup>51</sup> This issue was debated in the famous Diane Pretty case who requested her husband to end her life. She was frightened and distressed by the suffering and indignity she would have to bear if the disease was allowed to run its natural course. See *Pretty; X and Y v The Netherlands*; (1985) 8 EHRR 235; R (*Pretty*) v *Director of Public Prosecutions* (Secretary of State for the Home Department Intervening); [2001] UKHL 61; [2002] 1 AC 800; [2001] EWHC Admin 788; *Pretty v UK*; 2346/02.

<sup>52</sup> Mazanec, P. and Tyler M. K., "Cultural considerations in end-of-life care", *AJN*, Vol. 103 (2003) 50-58: 56. Also see Daaleman, T. P., "Placing religion and spirituality in end-of-life care", *JAMA*, Vol. 284 (2000) 2514-2517: 2514; Chater, K., and Tsai C. T., "Palliative care in a multicultural society: a challenge for Western ethics", *Australian Journal of Advanced Nursing*, Vol. 26 (2008) 95-100: 97.

<sup>53</sup> Billings and Krakauer, *supra*, n. 4 at 851.

<sup>54</sup> *Ibid* at p. 852.

<sup>55</sup> Griffiths, J., Bood A. and Weyers, H., *Euthanasia and law in the Netherlands*, (Amsterdam: Amsterdam University Press, 1998), 169. Also see Green, K., "Physician-assisted suicide and euthanasia: safeguarding against the slippery slope-the Netherlands versus the

secular approach is adopted in that the decision to die is considered to be a personal affair and is not subservient to the impact it has on public interests.<sup>56</sup> It is argued that modern law and ethics have recognised that the doctrine of sanctity of life can be superseded by the need to respect autonomy.<sup>57</sup> This forms the current position in countries such as the Netherlands, Belgium, Switzerland and the U.S states of Oregon, Washington, and Vermont where certain aspects of euthanasia are legalised.<sup>58</sup> The danger of loosening the restraint on an individual's choice to die is not entirely lost on governments which have permitted euthanasia; the right of a person to end his own life, although generally allowed, is subject to each country's set of regulatory procedures. Recognising that a patient's choice may not represent what he truly wants, the laws in the aforementioned countries place the burden of proof on the doctor's shoulders to verify

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United States", *Ind. Int'l & Comp. L. Rev.*, Vol. 13 (2) (2002) 639-681: 642-643; McLean, S. A. M., *Assisted dying: reflections on the need for law reform*, (Oxon: Routledge-Cavendish, 2007), 123-124.

<sup>56</sup> McLean, S. A. M., *supra*, n. 55 at p. 10.

<sup>57</sup> *Ibid* at pp. 30, 192.

<sup>58</sup> In 1995, the Rights of the Terminally Ill Act of the Northern Territory of Australia was passed permitting doctors to conduct euthanasia, but it was soon overturned by the Australian Senate in 1997. Four years after Australia's failed attempt, the Netherlands became the first country in the world to successfully legalise euthanasia and physician-assisted suicide. This was followed by Belgium in 2002, when the country passed a law to allow euthanasia. In 2009, Luxembourg became the second European country to legalise both euthanasia and physician-assisted suicide. In Colombia, euthanasia became permissible in 1997, following a decision delivered by its highest court that an individual has the right to end his life and doctors cannot be prosecuted for their involvement in the process. Fifteen years after its decriminalisation, a Colombian Senate commission approved the regulation of euthanasia. In the U.S., Oregon became the first state to decriminalise physician-assisted suicide in 1994 by virtue of its Death with Dignity Act; Washington followed suit with a similar Act in 2008; and in 2013, assisted death also became legal in Vermont. Switzerland on the other hand, adopts a rather unique approach to the subject matter; it is currently the only country in the world to legalise altruistic assisted suicide by non-doctors. Most recently in May 2014, Quebec's right-to-die bill was adopted in its national assembly.

that firstly, the patient was suffering from terminal illness with no prospect of recovery; secondly, the patient was in the right psychological state to make such a choice and thirdly, it was a voluntary and informed decision.<sup>59</sup> Widdershoven argues that the moral basis for the Dutch euthanasia practice is enconced in the ethics of care which are internalised in the process of mutual decision making, rather than the common principles of bioethics.<sup>60</sup> Thus, the other side of the euthanasia debate appears to view autonomy in two different facets; either as the primary principle for self-determination, or a value that forms only part of the moral justification and is overridden by the elements of responsibility, deliberation and care. These issues were deliberated at length in the landmark case of *Airedale NHS Trust v Bland*<sup>61</sup>, where the House of Lords discussed its legal justification in relation to the principle of sanctity of life and patient autonomy. The case concerned one Anthony Bland, a victim of the disaster at the Hillsborough Football Stadium who suffered irreversible damage to his cerebral cortex which rendered him to be in a persistent vegetative state. He was fed artificially and mechanically with a nasogastric tube and showed no cognitive response to his surroundings. All his natural bodily functions had to be operated with nursing intervention, requiring four to five hours of nursing attention by two nurses daily. After three and a half years of remaining in this condition, a court declaration was sought by Bland's attending doctor to cease further treatment, which involved extubation i.e. withdrawal of artificial nutrition and hydration and withholding of antibiotic treatment in case of infection. The declaration was based on a clinical assessment by medical experts that there was absolutely no hope of recovery for Bland and thus any medical intervention would be futile and not in the best interests of the patient. In arriving at its judgement, the court ruled that the principle of sanctity of life was not absolute; "it must yield to the right of self-determination".<sup>62</sup> The principle of self-determination requires that the patient's wishes be respected to

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<sup>59</sup> See for instance, Netherlands's Termination of Life and Assisted Suicide (Review Procedures Act) and Oregon's Death with Dignity Act 2001.

<sup>60</sup> Widdershoven, G. A. M., "Beyond autonomy and beneficence: the moral basis of euthanasia in the Netherlands", *Ethical Perspective*, Vol. 9 (2-3) (2002) 96-102: 98.

<sup>61</sup> [1993] All ER 821.

<sup>62</sup> *per* Lord Goff at p. 866.

the extent that if a patient of sound mind refuses to consent to a medical treatment which would prolong his life, the doctor responsible for his care must abide by the former's wishes, regardless of the fact that such refusal is unwise. In the case of an insensate patient like Bland who lacks the capacity to validly consent or refuse medical treatment, the lawfulness of such medical treatment depended upon whether it was in the best interests of the patient.<sup>63</sup> The court further held that doctors were not under an unqualified duty to prolong life at all costs; accordingly the duty to provide medical care "ceases when such treatment can serve no humane purpose".<sup>64</sup> In *Bland's* case, the futility of the treatment in providing him any quality of life ethically justified its termination.<sup>65</sup>

A patient's right to autonomy was reiterated in *Ms B v An NHS Hospital Trust*.<sup>66</sup> Here, the case involved a patient who was mentally competent and had repeatedly yet unsuccessfully requested for the withdrawal of medical therapy to which she was subjected. Ms B suffered a spinal cavernoma, which necessitated neurological surgery to remove it. During the course of her hospitalisation and treatment, she executed a living will stating that if at any point of time, she was incapable of giving instructions, she wanted treatment to be withdrawn if she was suffering from a life-threatening condition, permanent mental impairment or permanent unconsciousness. Unfortunately, as a result of the surgery, Mrs B became completely paralysed from the neck down and was treated with a ventilator to ease her respiratory problems. She eventually regained some movement in her head and was able to speak, pursuant to which she requested to her clinicians on several occasions to have the ventilator removed. The doctors were not prepared to do so as they considered it to not be in her best interests i.e. it would inevitably lead to her death. In allowing Mrs B's claim for a declaration that the hospital had been treating her unlawfully, the court upheld the principle of self-determination, referring to the judgements delivered by the bench in *Bland* on the interface between the two conflicting principles of autonomy and preservation of life. It was accordingly ruled that the principle of "best interests" was not applicable in cases where the patient had the mental capacity to make relevant decisions

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<sup>63</sup> *per* Sir Thomas Bingham at p. 843.

<sup>64</sup> *per* Lord Hoffman at p. 856.

<sup>65</sup> *per* Lord Goff at p. 870.

<sup>66</sup> [2002] All ER (D) 362 (Mar).

about her medical treatment, and therefore a doctor was under an obligation to respect the wishes of the patient, even if it was plain to all parties, including the patient, that death would ensue.

However, respect for autonomy does not entirely necessitate complete discretion at the hands of the patient. Information sharing and discussions between the parties involved in the patient's care facilitate ethical decision making and concomitantly enhance patient autonomy. It is to be noted that doctors have a moral obligation that may outweigh their duty to respect a patient's wishes, particularly where end-of-life decisions are concerned.<sup>67</sup> A doctor's obligation to his patient extends beyond the prevention of harm, and includes restoration and improvement of the quality of life.<sup>68</sup> Further, patients' preferences are not decisive unless a beneficial medical perspective is present.<sup>69</sup> Therefore, doctors are not obliged to honour requests for interventions that confer no medical benefit to the patient or treatments that would expose the patient to more harm than good, as this would constitute a direct violation of the values of the medical profession, and a disrespect towards the concept of patient autonomy.<sup>70</sup> Billings and Krakauer argue that doctors should not encourage active participation by the patient in technical aspects of medical decisions and non-beneficial interventions should not even be offered in the first place, as this would "promote the appearance of autonomy when in fact the patient may be harmed."<sup>71</sup> Correspondingly, it has been largely advocated that a patient's right to autonomy does not extend to even more complex situations such as assistance in dying.<sup>72</sup> It is considered unethical for doctors to undermine their commitment to professional integrity, at the core of which stands their moral obligation to primarily protect the patients' best interests, by succumbing to a patient's request to die.

Although such refusal to accede to the patient's wishes may be seen as an infraction to the patient's individual liberty, it is argued

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<sup>67</sup> Baumgarten, *supra*, n. 3 at p. 3.

<sup>68</sup> *Supra*, n. 6 at p. 28.

<sup>69</sup> Brett and McCullough, *Supra*, n. 3 at p. 149.

<sup>70</sup> *Ibid* at p. 150. Also see Billings and Krakauer, *supra*, n. 4 at 852.

<sup>71</sup> Billings and Krakauer, *supra*, n. 4 at 852.

<sup>72</sup> Baumgarten, *supra*, n. 3 at p. 3. Also see Rathor, M. Y. and Abdul Rani, M. F., "Euthanasia and physician-assisted suicide: a review from Islamic point of view", *International Medical Journal Malaysia*, Vol. 11 (1) (2012) 63-68: 64.

that terminating one's life is in fact antithetical to his right to wilful and free consent as it puts an end to the possibility of the patient's right to exercise autonomy.<sup>73</sup> Another view is that due to the inconstancy of values and emotions experienced by terminally ill patients, "one cannot assume that autonomy is fully restorable or preservable"<sup>74</sup> in such cases. Individual autonomy can be significantly compromised in seriously ill patients due to delirium and decreased cognitive functions which impair their decision-making capacity.<sup>75</sup> Orentlicher points out that since a person's choice to end his life may not be a genuine expression of autonomy, the common argument propounded is that it would be rightful to prohibit the act entirely.<sup>76</sup>

Many countries state explicitly in their legislations that a patient's request to end his own life would amount to suicide and therefore unlawful, and any doctor who aids and abets the patient in such circumstances may be committing a criminal offence. The Malaysian Penal Code, for example, makes it clear that a doctor who deliberately takes active steps to cause death or hasten death of his terminally ill patient even at the request of his patient would be committing culpable homicide. Section 299 provides that "whoever causes death by doing an act with the intention of causing death, or with the intention of causing such bodily injury as is likely to cause death, or with the knowledge that he is likely by such act to cause death, commits the offence of culpable homicide." Explanation 1 given under the section states that "a person who causes bodily injury to another who is labouring under a disorder, disease, or bodily infirmity, and thereby accelerates the death of that other, shall be deemed to have caused his death." This clearly fits the situation of active voluntary euthanasia and will make it unlawful, amounting to culpable homicide. Punishment for culpable homicide not amounting

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<sup>73</sup> Rathor, M. Y. and Abdul Rani, M. F., *supra*, n. 72 at p. 64. Also see Orentlicher, D., "The alleged distinction between euthanasia and the withdrawal of life-sustaining treatment: conceptually incoherent and impossible to maintain", *U. Ill. L. Rev.*, No. 3 (1998) 837-860: 841.

<sup>74</sup> *Supra*, n. 6 at p. 27. Also see Tonelli, M. R. and Misak, C. J., "Compromised autonomy and the seriously ill patient.", *Chest* Vol. 137 (4) (2010) 926-931: 927.

<sup>75</sup> Tonelli, M. R. and Misak, C. J., *supra*, n. 73 at p. 927. Also see Billings and Krakauer, *supra*, n. 4 at p. 850.

<sup>76</sup> Orentlicher, *supra*, n. 73 at pp. 850-851.

to murder is provided under section 304 which states that “whoever commits culpable homicide not amounting to murder shall be punished (a) with imprisonment for a term which may extend to twenty years, and shall also be liable to fine, if the act by which the death is caused is done with the intention of causing death, or of causing such bodily injury as is likely to cause death; or (b) with imprisonment for a term which may extend to ten years, or with fine, or with both, if the act is done with the knowledge that it is likely to cause death, but without any intention to cause death, or to cause such bodily injury as is likely to cause death.” In the United Kingdom, a doctor who deliberately takes active steps to cause death or hasten death of a terminally ill patient would be committing murder<sup>77</sup>. The court in *Airedale NHS Trust v Bland*<sup>78</sup> held that active euthanasia or doing a positive act to end life is unlawful as it is a direct violation of the principle of sanctity of life. Active measures to cut short the life of a terminally ill patient are forbidden. As long as there is an intention to kill, it is sufficient to make it an unlawful act. The reason behind the intention makes no difference and even if the patient requests for termination and consents to the procedure, active voluntary euthanasia would still be unlawful. In *R v Donovan*<sup>79</sup>, it was held that if an act is unlawful in the sense of being in itself a criminal act, it cannot be rendered lawful merely because the person to whose detriment it is done consents to it. No person can license another to commit a crime.

### iii. Patient Autonomy and the Right of Privacy

The English common law has not recognised invasion of privacy rights as breach of a protected right under Tort Law.<sup>80</sup> Hence, it is also not actionable under Malaysian law of tort pursuant to section 3 of the Civil Law Act 1956. However, although violation of privacy is

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<sup>77</sup> The elements of *actus reus* and *mens rea* for murder have to be satisfied.

<sup>78</sup> [1993] 1 All ER 821.

<sup>79</sup> [1934] 2 KB 498.

<sup>80</sup> Clerk, J. F., Lindsell, W. H. B. and Dugdale, A. M., *Clerk and Lindsell on torts*, (London: Sweet and Maxwell, 2000), 19, para. 1-34, which state that privacy remains an interest unprotected by the English law of torts.

not itself a tort, violation of privacy can amount to violation of some other interest protected in tort. This may range from trespass to land to injury to health resulting in repeated incursions of privacy or breach of confidence. Nevertheless, the case of *Lee Ewe Poh v Dr Lim Teik Man & Anor*<sup>81</sup> gives credence to the patient's rights of privacy and affirmed that such invasion would constitute a cause of action. In *Lew Ewe Poh*, the plaintiff/patient brought an action against the defendant, a colorectal surgeon, that the photographs he had taken of her private parts without her consent during a procedure constitute an invasion of her privacy rights under the common law. The photographs were taken while the patient was unconscious and under anaesthesia. The plaintiff later learned from the nurse that photographs showing her anus were taken without her prior knowledge and consent. The defendant surgeon claimed that "infringement, invasion or violation of privacy" was not a recognised tort or a cause of action in Malaysia. It was acceptable medical practice for photographs to be taken in the course of surgical procedure in a clinical environment and intended for the plaintiff's medical record. It was further submitted that the plaintiff's identity was not known in these photographs. However, the court held consent was an absolute requirement especially since the photographs involved images of her intimate parts.<sup>82</sup> Invasion of privacy of a female in relation to her modesty, decency and dignity is a cause of action and thus actionable. As a doctor, the defendant ought to be aware of the need to obtain the patient's prior consent for such photographs to be taken, particularly, when it involves the private parts of the patient. Further, there was publication of the photographs as they were seen by the nurse. This case depicts that the right of privacy of the patient needs to be fully respected in modern health care setting. The medical profession needs to be aware that prior consent of the patient is essential before invading the patient's privacy. In this respect, patient autonomy has been elevated to a level that even if an action is taken in a clinical environment for the best interest of the patient, the patient still needs to be informed in all aspects of the medical procedure.

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<sup>81</sup> [2011] 1 MLJ 835.

<sup>82</sup> The court relied on the Court of Appeal's judgment in *Maslinda bt Ishak v Mohd Tahir bin Osman & Ors* [2009] 6 MLJ 826; [2009] 6 CLJ 653 in which the court recognised and affirmed invasion of privacy as a cause of action.

## THE ARGUMENTS AGAINST ABSOLUTE AUTONOMY AND A NEED FOR SHARED DECISION MAKING

While it is generally agreed that respect for patient autonomy must guide the decision-making process, many of the proponents of autonomy recognise that it does not stand as an absolute and unequivocal doctrine.<sup>83</sup> True autonomy is not achieved by allowing the patient to unilaterally direct his own course of medical care with total independence from any external influence<sup>84</sup>, relegating the doctor to the role of a technical expert whose duty is to provide the relevant medical facts to the patient and no more.<sup>85</sup> In fact, to do so would instead infringe the patient's autonomy and defeat the patient's interests, as the patient would be left to make medical decisions on his own without full understanding and proper deliberation of what the situation entails.<sup>86</sup> If doctors, for the sake of honouring individual liberty, were to allow patients to freely decide without making informed choices, these could place unreasonable responsibility on patients and lead them to make unwise decisions.<sup>87</sup> Further, patients could be left feeling abandoned rather than autonomous if their doctors refuse to do more than provide them with options and leave it entirely to the patients' discretion to choose.<sup>88</sup> Consequently, complying with patients' demands for unnecessary interventions that

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<sup>83</sup> See for instance, Komrad, M., "A defence of medical paternalism: maximising patients' autonomy", *Journal of Medical Ethics*, (1983): 38-44; Baumgarten, *supra*, n. 3.

<sup>84</sup> Pellegrino, E., "Patient and physician autonomy: conflicting rights and obligations in the physician-patient relationship", *J. Contemp. Health L. & Pol'y*, Vol. 10 (1994) 47-68: 50.

<sup>85</sup> This is known as the "informative model". See *supra*, n. 1 at p. 20; Emanuel, E. and Emanuel, L., "Four models of the physician-patient relationship", *JAMA*, Vol. 267 (16) (1992) 2221-2226: 2221; Baumgarten, *supra*, n. 3 at p. 3.

<sup>86</sup> *Supra*, n. 17 at p. 153. Also see Billings and Krakauer, *supra*, n. 4 at p. 850.

<sup>87</sup> Entwistle, V., Carter S., Cribb A., et al, "Supporting patient autonomy: the importance of clinician-patient relationships", *Journal of General Internal Medicine*, Vol. 25 (7) 741-745: 742. Also see Baumgarten, *supra*, n. 3 at p. 5; Billings and Krakauer, *supra*, n. 4 at p. 849.

<sup>88</sup> Entwistle et al, *supra*, n. 87 at p. 742.

thwart proper clinical reasoning may also debilitate the professional integrity of the medical profession, as it “results in a non-deliberative, rote practice style that undermines clinical excellence.”<sup>89</sup> The above discussion lends credence to the contention that striking a balance between autonomy and guided paternalism best promotes and preserves a person’s right to free consent.<sup>90</sup> The doctor not only provides the patient with the relevant medical information, but both doctor and patient engage in discussions on the medical and ethical aspects, including deliberation of the patient’s concerns, values and beliefs. A decision is then reached collectively through this ‘partnership’.<sup>91</sup> Consequently, this process of shared decision making allows the doctor to honour his professional integrity and moral obligations to the patient while maintaining due respect for the patient’s autonomy,<sup>92</sup> thus providing a more conducive environment for mutual trust and understanding to take place.

Some argue that although respecting the patient’s wishes is an integral part of shared decision making, this does not mean that the doctor cannot attempt to change the patient’s mind when such effort can improve the quality of the patient’s decision and protect him from unnecessary harm.<sup>93</sup> Levy suggests that “there may be good grounds for some degree of paternalistic interference with individual choice when this interference can reasonably be expected to promote the pursuit of the good life”<sup>94</sup>, as this will serve to enhance patients’ effective autonomy rather than limit it.<sup>95</sup> It is universally agreed among the biomedical community that doctor

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<sup>89</sup> Brett and McCullough, *supra*, n. 3 at p. 149. Also see *supra*, n. 84 at p. 58.

<sup>90</sup> *Supra*, n. 1 at p. 20.

<sup>91</sup> This is termed by ethicists as the “deliberative model”. In this relationship, the doctor assumes the role of a teacher or friend, “engaging the patient dialogue on what course of action would be best”. See Emanuel, E. and Emanuel, L., *supra*, n. 85 at p. 2222; *Supra*, n. 17 at p. 154

<sup>92</sup> *Supra*, n. 1 at p. 20.

<sup>93</sup> See for instance, Levy, N., “Forced to be free? Increasing patient autonomy by constraining it”, *Journal of Medical Ethics*, (2012): 1-8; Entwistle et al, *supra*, n. 87; *Supra*, n. 1; *Supra*, n. 84.

<sup>94</sup> Levy, N., *supra*, n. 93 at p. 2.

<sup>95</sup> *Ibid*. Also see Entwistle et al, *supra*, n. 87 at p. 744.

autonomy and moral integrity must also be respected, and thus it is justified for doctors to refuse to accede to a patient's decision that may expose the patient to unwarranted harm.<sup>96</sup> As Pellegrino points out, "autonomy needs content", and "[i]t is the physician's beneficent obligation to enhance, empower and enrich the patient's capacity to be autonomous".<sup>97</sup> Autonomy is therefore a "double-way street", requiring both patient and doctor responsibility.<sup>98</sup> Further, the proponents of the equilibrium between autonomy and paternalism assert that such an approach entails a positive synergy between the ethical principles of beneficence and non-maleficence.<sup>99</sup> Paternalism is in essence motivated by the doctor's moral obligation to do what would be in the best interests of the patient and to prevent harm to the patient; if exercised to a certain degree and within a balanced dimension, it would serve to facilitate and enhance the patient's capacity for self-determination in accordance with the patient's own perspectives.<sup>100</sup> Pellegrino and Thomasma go further to suggest that autonomy and paternalism are guided and superseded by the duty of beneficence, in that "the choice of whether one acts to foster autonomy, or acts paternalistically should be based on that which most benefits the patient".<sup>101</sup>

In sum, it is generally agreed that neither autonomy nor the other bioethical principles should be treated exclusively of one another. Although patient autonomy is the central theme of bioethics, it is "not an all-or-nothing affair"<sup>102</sup> and neither does it prevail over all other values. The concern raised by many ethicists is that the prevalent practice of placing too much emphasis on patient autonomy is a defective approach and corrodes the moral integrity of doctors. Accordingly, such ethical principles should be applied in congruence with one another, leading to a harmonious interplay of values within the spectrum of bioethics.

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<sup>96</sup> *Supra*, n. 1 at p. 14. Also see *supra*, n. 84 at p. 58.

<sup>97</sup> *Supra*, n. 84 at p. 51.

<sup>98</sup> da Rocha, *supra*, n. 18 at p. 61.

<sup>99</sup> See for instance, *supra*, n. 6 at pp. 39-41; *Supra*, n. 17 at p. 154.

<sup>100</sup> *Supra*, n. 17 at p. 154.

<sup>101</sup> *Supra*, n. 6 at p. 42.

<sup>102</sup> Tonelli and Misak, *supra*, n. 73 at p. 930.

## THE LIMITATIONS OF ABSOLUTE AUTONOMY IN MODERN MEDICAL PRACTICE

The general consensus among many ethicists is that the duty to respect autonomy is not absolute and “does not entail providing a patient with any intervention on demand”.<sup>103</sup> A broader view of autonomy is preferred, requiring the patient to be able to understand and coherently deliberate on clinical decisions based on the medical and value discussions with his doctor. Due to the fact that true autonomy requires that the patient be able to fully discern the ramifications of the choices that he makes, free from external control and pressure, the exercise of autonomy is therefore limited in cases where the person has diminished capacity to decide for himself.<sup>104</sup> This accordingly applies to children who are very young and those who suffer from mental retardation or mental incompetency. Such category of patients, due to their restricted or lack of ability to form mature and rationale thoughts, are heavily dependent on outside influences or authorities to make decisions in their best interests. Some argue that the full measure of autonomy is also compromised in patients with serious illness, although they may still possess basic decision-making capacity.<sup>105</sup> Factors such as pain, systemic weakness, delirium, depression and anxiety could distort the cognitive function of terminally ill patients and impair their ability and perception to make an autonomous choice; as Baumgarten points out, in the face of illness, “a patient’s current choice might not represent what even the patient himself *truly* wants.”<sup>106</sup>

Another limitation to autonomy is when patients, without justifiable reasons, request for futile treatments that are not medically indicated, offer no benefit or may be harmful to the patient.<sup>107</sup> A doctor

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<sup>103</sup> Billings and Krakauer, *supra*, n. 4 at p. 850.

<sup>104</sup> See for instance, *supra*, n. 1 at p. 13; Komrad, *supra*, n. 83 at pp. 41-42; Spriggs, M., *Autonomy and patients’ decisions*, (Lanham: Lexington Books, 2005), 117, 135; *Supra*, n. 6 at pp. 29-30

<sup>105</sup> Tonelli and Misak, *supra*, n. 73 at pp. 927-928. Also see Komrad, *supra*, n. 83 at p. 41; Baumgarten, *supra*, n. 3 at p. 5; Billings and Krakauer, *supra*, n. 4 at p. 850.

<sup>106</sup> Baumgarten, *supra*, n. 3 at p. 5.

<sup>107</sup> See for instance, Baumgarten, *supra*, n. 3 at p. 4; *Supra*, n. 84 at p. 68; Lantos, J., Matlock, A. and Wendler, D., “Clinician integrity and limits to patient autonomy”, *JAMA*, Vol. 305 (5) (2011) 495-459:

is thus, not bound to comply with a patient's demand for unjustified interventions or unusual care that would not be in the patient's best interests. According to Brett and McCullough, "a patient's preference for a diagnostic or therapeutic intervention is not decisive unless a modicum of potential benefit, viewed from a conventional medical perspective, is present".<sup>108</sup> If such benefit is absent, then doctors should not provide such intervention. Some argue that this is similarly applicable where the patient's request would be against public interest i.e. detrimental to the rights of others.<sup>109</sup> It follows that a doctor has the right to refuse if the wishes of the patient violate the moral values of the medical profession, which include the principles of beneficence and non-maleficence.

In cases of euthanasia or assisted suicide, many ethicists agree that a patient's autonomy does not extend to the right to die. The arguments put forth, for the most part, have been on the basis of the sanctity of life, doctors' professional integrity and beneficence-based duty, and the subjectivity of genuine consent occupying a patient's choice to terminate his life. There are differences in opinion on whether there exists a moral distinction between killing (active euthanasia) and letting die (passive euthanasia such as withholding and withdrawal of treatment). One of the arguments supporting the difference between the two is based on intent; it is morally justified to withdraw treatment with the intention to relieve the patient of the burdens associated with that treatment, even if by doing so, death is foreseeably yet unintentionally hastened.<sup>110</sup> Thus, as opposed to active euthanasia, death is not the aim. McLachlan illustrates the moral difference between killing and letting die as follows:

“[O]ur moral obligations with regard to killing people are different from our obligations with regard to letting them die. We are obliged to refrain from killing each and everyone. We do not have a similar

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<sup>108</sup> Brett and McCullough, *supra*, n. 3 at p. 149.

<sup>109</sup> Stirrat, G. and Gill, R., "Autonomy in medical ethics after O'Neill", *Journal of Medical Ethics*, Vol. 31 (3) (2005) 127-30: 130.

<sup>110</sup> See for instance, Kinsella, J., and Booth, M. G., "Ethical framework for end of life decisions in intensive care in the UK", *J Natl Inst Public Health*, Vol. 56 (2007) 387-392: 388-389.

obligation to try (far less to continue to try) to prevent each and everyone from dying.”<sup>111</sup>

Thus, seen from the perspective of autonomy, a patient has the right to forego treatment, but not the right to request for assistance to kill himself. Correspondingly, a doctor who refuses to accede to the wishes of a patient to withdraw medical therapy infringes the patient's autonomy, while a doctor who refuses the request of a patient to be killed does not. While active euthanasia is criminally sanctioned in the U.K, the legal position in the U.K with regard to passive euthanasia is in favour of greater patient autonomy. To reiterate what has been stated previously, the landmark case of *Airedale NHS Trust v Bland*<sup>112</sup> enunciates the principle that the principle of sanctity of life is not absolute; “it must yield to the right of self-determination”<sup>113</sup> Such individual liberty however is limited in the case of a patient who lacks the capacity to validly consent or refuse medical treatment, in which what doctors decide to be in the best interests of the patient must necessarily take precedence.<sup>114</sup> This judicial principle accords with the earlier discussion on limitation of autonomy with respect to those with impaired cognitive function. It is suggested that where autonomy is constrained, limited paternalism steps in to compensate. Komrad propounds this view, stating that “[t]he *raison d’être* of limited paternalism is to preserve an individual's freedom as much as possible in the hope of eventually broadening it.”<sup>115</sup> Accordingly, both autonomy and paternalism are complementary components in the doctor-patient relationship. As Lantos, Matlock and Wendler point out, “Clinicians respect patient autonomy, but nonetheless constrain the range of choices over which patients may exercise autonomy. Patients may choose among the options within the proffered range, but they cannot go beyond it. In this way, patient autonomy has boundaries and limits.”<sup>116</sup>

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<sup>111</sup> McLachlan, H., “The ethics of killing and letting die: active and passive euthanasia.”, *Journal of Medical Ethics*, Vol. 34 (8) (2008), 636-8: 636.

<sup>112</sup> [1993] 1 All ER 821.

<sup>113</sup> *Ibid per* Lord Goff at p. 866.

<sup>114</sup> *Ibid per* Sir Thomas Bingham at p. 843.

<sup>115</sup> Komrad, *supra*, n. 83 at p. 42.

<sup>116</sup> Lantos, J., Matlock, A. and Wendler, D., *supra*, n. 107 at p. 497.

## PATIENT AUTONOMY AND ITS LIMITATIONS UNDER THE *SHARĪ'AH*

The *Sharī'ah* or Islamic law is based on two primary sources, the Holy Qur'an<sup>117</sup> and the *Sunnah* of Prophet Muhammad (peace be upon him).<sup>118</sup> The secondary source of the *Sharī'ah* is found in *ijtihad* (deductive reasoning). The guiding principles, rules and regulations in the main sources govern the Islamic way of life, and together with *ijtihad*, provide a comprehensive moral and juridical framework to address and resolve issues relating to human conditions. It prescribes for a balanced way of life in both its materialistic and spiritual aspects, which is firmly based on the concept of monotheism i.e. belief in the Oneness of God.<sup>119</sup> In Islamic jurisprudence, each deliberation towards resolving any given issue must be consistent with and founded upon the principles laid down in the Holy Qur'an and the *Sunnah*. It follows that the five fundamental principles which are known as *maqasid al-sharī'ah* must be observed: preservation of life, protection of an individual's freedom or belief, maintenance of intellect, preservation of honour and integrity, and protection of property.<sup>120</sup>

Congruently, the same framework applies to bioethical decisions. The main principle in Islamic bioethics is the sanctity of human life. This ruling is ordained in the Holy Qur'an in the following verse: "Do not take life which God has made sacred except in the course of Justice".<sup>121</sup> It is accordingly forbidden for anyone to deliberately end a life: "Whosoever takes a human life, for other than murder or corruption in the earth, it is as if he has taken the life of all

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<sup>117</sup> The Holy Book which Muslims believe to be the word of God Almighty.

<sup>118</sup> The words, conduct and tacit approval of Prophet Muhammad (peace be upon him).

<sup>119</sup> Rathor, M. Y., Abdul Rani, M. F., Mohamad Shah A. S. et al, "The principle of autonomy as related to personal decision making concerning health and research from an 'Islamic viewpoint'" (2011), Vol. 43, 27-34 at p. 28.

<sup>120</sup> Gatrad, A R, and Sheikh, A., "Medical ethics and Islam: principles and practice", *JIMA Archives of Disease in Childhood*, Vol. 84 (1) (2001) 72-75: 73.

<sup>121</sup> *Al-Qur'ān* 6:151.

of mankind.”<sup>122</sup> In Islam, the underlying reason for the impermissibility on euthanasia and all forms of suicide is that the decision to terminate a life vitiates one’s belief in God’s absolute mercy.<sup>123</sup> It thus follows that the saving of a life is considered one of the highest merits and imperatives in Islam.<sup>124</sup> Prophet Muhammad’s (peace be upon him) traditions also confirm that killing a human being is one of the worst cardinal sins. The Prophet (peace be upon him) has been quoted as saying: “The most serious of cardinal sins are ascribing a partner to God, killing a human being, being undutiful to one’s parents, and making a false statement”<sup>125</sup> and in another version “giving a false testimony” is added.<sup>126</sup> The Holy Qur’an is also clear in prohibiting a person from committing suicide. In *Surah al-Nisa*, it is stated to the effect: “Do not kill yourselves as God has been to you very Merciful”.<sup>127</sup> These authorities from the Holy Qur’an and *Hadith*<sup>128</sup> illustrate the sanctity of human life, prohibition of killing a human being with no justification, and prohibition of killing oneself. Thus, killing a person to ease his suffering even though it is at the request of the person is inconsistent with Islamic law, regardless of the different names given to the procedure, such as active voluntary euthanasia, assisted suicide or mercy killing. A person in such a situation should persevere patiently with the available medical treatment as the reward for such patience in the Hereafter is tremendous, as promised in *Surah al-Zumar*:

<sup>122</sup> *Al-Qur’ān* 5:32.

<sup>123</sup> Rathor and Rani, *supra*, n. 72 at p. 65.

<sup>124</sup> Zahedi, F., Larijani, B. and Bazzaz J. T., “End of life ethical issues and Islamic views”, *Iran J Allergy Asthma Immunol*, Vol. 6 February (2007) 5-15: 11. Also see Rathor and Rani, *supra*, n. 72 at p. 64.

<sup>125</sup> Quoted by *al-Bukhaari*.

<sup>126</sup> *Al-Nisaai*, in his book of the Prophet’s traditions, quotes a statement by the Prophet that says, “To kill a believer is more serious, in God’s eyes, than the earth coming to an end.” *Al-Tirmithi* quotes the Prophet (peace be upon him) as saying, “If the dwellers of heaven and the dwellers of earth combined together were responsible for a believer’s death, God, the Most Sublime, would place them all, turned upside down, in Hell.”

<sup>127</sup> *Al-Qur’ān* 4:29.

<sup>128</sup> The words of Prophet Muhammad (peace be upon him), which forms the *Sunnah*.

And those who patiently persevere will truly receive a reward without measure.<sup>129</sup>

Thus, Muslims believe that pain and illness are a natural process of life and more importantly, tests from God to confirm a believer's level of faith. The Qur'an states,

O all you who believe, seek your help in patience and prayer; surely God is with the patient . . . Surely We will try you with something of fear and hunger, and diminution of goods and lives and fruits; yet give thou good tidings unto the patient who, when they are visited by an affliction, say, 'Surely we belong to God, and to Him we return'; upon those rest blessings and mercy from their Lord, and those - they are the truly guided.<sup>130</sup>

This however does not mean that Muslims are required to endure suffering without searching for a cure; on the contrary, Islam directs those who are sick to conscientiously and patiently seek medical treatment: "And who despairs of the mercy of his Lord, but those who are misguided."<sup>131</sup> In a *Hadith*, it is narrated that Prophet Muhammad (peace be upon him) said, "There is no disease that Allah has sent down except that He has also sent down its treatment."<sup>132</sup>

The bioethical principles of autonomy, beneficence, non-maleficence and justice which form the fundamentals of Western bioethics are similarly imbued in the Islamic precepts relating to medicine. While there are many similarities in the approach adopted by the Western and Islamic systems, there exist some notable differences between the two models with regard to the application of patient autonomy. Such differences emanate from the disparate sources that form the substratum of Western and Islamic bioethics respectively. As highlighted in the preceding paragraphs, the Islamic model is derived from a divine order, from which moral principles applicable to medicine are acknowledged and legislated. The Western concept is on the other hand secular and primarily drawn from human

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<sup>129</sup> *Al-Qur'an* 39:10

<sup>130</sup> *Al-Qur'an* 2:153-57.

<sup>131</sup> *Al-Qur'an* 15:56.

<sup>132</sup> *Sahih al-Bukhaari*, Book 76, Hadith 1.

reason and experience, and there exist variable ethical theories on the validity of moral cognition.<sup>133</sup> Autonomy is recognised and held high in Islamic teachings in that no one is entitled to dispose of the right of an individual without the latter's permission.<sup>134</sup> However, the right to autonomy in Islam is not absolute and is qualified in the following respects:

(1) ***Decision making must concede and be based on knowledge.*** Autonomy can only be exercised if the patient participates in the decision-making process with the ability to understand and make intelligent decisions,<sup>135</sup> following an informed discussion with his doctor. If there is a prevailing standpoint on the matter in Islam, the doctor and the patient is obliged to comply and act accordingly with it,<sup>136</sup> overriding any conflicting preference that they may personally have;

(2) ***Public interests supersede individual considerations.*** In Islam, individual welfare is intrinsically connected to one's family and community.<sup>137</sup> A person's freedom of choice is thus contingent upon the responsibilities that he has towards others; to form an ethical decision, there must accordingly be a balance between the right of the individual, the wishes of family members and the concerns of society as a whole.<sup>138</sup> This is in accordance with the principle of *istislah*<sup>139</sup> in Islamic jurisprudence;

<sup>133</sup> See *supra*, n. 1 at pp. 389-404.

<sup>134</sup> Aksoy, S., and Elmali, A., "The core concepts of the 'four principles' of bioethics as found in Islamic tradition", *Med Law* Vol. 21 (2002) 211-214: 216-217. Also see Albar, M. A., "Seeking remedy, abstaining from therapy and resuscitation: an Islamic perspective", *Saudi J Kidney Dis Transplant*, Vol. 18 (4) (2007) 629-637: 634; Rathor and Rani, *supra*, n. 72 at p 63.

<sup>135</sup> Rathor and Rani, *supra*, n. 72 at p. 63.

<sup>136</sup> Aksoy and Elmali, *supra*, n. 134 at p. 216.

<sup>137</sup> Sachedina, A., "End-of-life: the Islamic view", *The Lancet*, Vol. 366 (2005) 774-779: 776. Also see Rathor et al, *supra*, n. 120 at p. 29.

<sup>138</sup> Rathor and Rani, *supra*, n. 72 at p. 63.

<sup>139</sup> The principles of *istislah* is one of the methods applied in Islamic jurisprudence to seek the best solution in order to serve the general interest of the community.

(3) ***Restriction of autonomy in end-of-life decisions.***

In cases of active euthanasia, the Islamic position on the sanctity of life makes it clear that there can be no concept of free consent and personal liberty.<sup>140</sup> Where other aspects of end-of-life decisions are concerned, such as withdrawal and withholding of futile treatments, apart from the principle of *istislah*, the Islamic legal maxim, “no harm shall be inflicted or reciprocated” (non-maleficence) governs the approach to Islamic medical ethics including the principle of autonomy. In cases of passive euthanasia, which include withdrawal and refusal of life-sustaining treatments and terminal sedation, the decision cannot be an individually autonomous decision, but rather one which is jointly made pursuant to discussions between all of those concerned, such as the medical team, the patient, his family members, and at times religious authorities.<sup>141</sup>

(4) ***Obedience towards God supersedes the obligation to respect patient’s wishes.***

The general philosophy in Islamic medicine is that God is the Ultimate Healer and the doctor is the instrument that God uses to treat people and alleviate suffering.<sup>142</sup> The doctor-patient relationship therefore takes on a more meaningful dimension than the Western model; in Islam a doctor is not only accountable to the patient in

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<sup>140</sup> This view is embodied in the provisions of the Islamic Code of Medical Ethics, adopted at the First International Conference on Islamic Medicine which took place in Kuwait in 1981

<sup>141</sup> Athar, S., “Ethical decision making in patient care: an Islamic perspective”, *Health concerns for believers: contemporary issues*, Athar, S (ed.), (Kazi Publications Inc., 1996) 59-64, 63. Available at [http://www.islam-usa.com/index.php?option=com\\_content&view=article&id=349&Itemid=](http://www.islam-usa.com/index.php?option=com_content&view=article&id=349&Itemid=). Also see Sachedina, *supra*, n. 137 at p. 778; Rathor and Rani, *supra*, n. 72 at p. 67.

<sup>142</sup> Sharif Kaf Al-Ghazal, “The influence of Islamic philosophy and ethics on the development of medicine in the Islamic civilisation”, *Foundation for Science Technology and Civilization* 1-12, (2007): 4. Also see Rathor and Rani, *supra*, n. 72 at p. 65; n.a., *Islamic Code of Medical Ethics*, First International Conference on Islamic Medicine, Kuwait, 1981.

the performance of his duties, but more importantly, is answerable to God for his actions.<sup>143</sup> Therefore, he cannot use patient autonomy as a justification to commit that which is forbidden in Islam<sup>144</sup>; and

(5) ***Duties of beneficence and non-maleficence may in certain situations take precedence over autonomy.*** It is the duty of a doctor to do what is in the best interests of the patient as a whole and prevent the patient from harm. In emergency cases for example, doctors are allowed to proceed with treatment or interference to save the patient's life although it may be against the patient's wishes, as long as they follow the proper medical procedures. The justification of such course of action is explained in the Islamic Code of Medical Ethics:

“The ‘bad’ inherent in not saving the patient outweighs the presumptive ‘good’ in leaving him to his self-destructive decision. The Islamic rule proclaims that ‘warding off’ the ‘bad’ takes priority over bringing about the ‘good’. The Prophetic guidance is “Help your brother when he is right and when he is wrong”. When concurring with helping a brother if right but surprised at helping him when wrong, the Prophet answered his companions: “Forbid him from being wrong...for this is the help he is in need of”.

A doctor may also in exercising his duties of beneficence and non-maleficence, refuse to accede to the request of a patient to administer therapy that would be futile.<sup>145</sup> Further, in Islam, individual liberty “is constrained by the harm it causes others”<sup>146</sup> which substantiates the subservience of autonomy to non-maleficence in certain cases. To this end, guided paternalism is required in certain respects to ensure that the best interests of the patient and society at large are preserved.

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<sup>143</sup> Sharif Kaf Al-Ghazal, *supra*, n. 142 at p. 4.

<sup>144</sup> Islamic Code of Medical Ethics, *supra*, n. 142.

<sup>145</sup> Rathor et al, *supra*, n. 119 at p. 31.

<sup>146</sup> *Ibid* at p. 30. Also see Rathor and Rani, *supra*, n. 72 at p. 63.

Similar to the Western model, in Islam, the bioethical principles of autonomy, beneficence and non-maleficence do not operate exclusively of one another, but rather constitute a harmonious synergy, which promotes and enhances the doctor-patient relationship. The participation of the doctor in effectively communicating the necessary information to the patient and his sensitivity towards the overall well-being of the patient and his family, will serve to facilitate the patient in arriving at a sound autonomous decision. Further, in cases where the patient is incapable of decision making, the application of such ethical principles will actuate a concerted effort on the part of the doctor to ascertain what would be in the best interests of the patient.<sup>147</sup>

## CONCLUSION

The importance of patient autonomy in the field of medicine cannot be refuted, as self-determination is a prerequisite for the liberty of the individual and is a value worth protecting. Both Islamic and Western bioethics perceive autonomy as an integral element that must be respected in developing and preserving a positive and ethical doctor-patient relationship. The eclipse of paternalism and deference towards greater patient autonomy which currently form the trend in modern medical practice however, have raised a lot of concern among ethicists and doctors alike. There is general agreement that the fundamental liberty of the individual to self-determination cannot and should not be undermined. Allowing unrestricted exercise of this right however, would place untenable responsibility on the patient in making complex medical decisions and relegate the doctor's duty to no more than a passive informer, rather than one whose duty is to care for the patient, prevent harm and act in the latter's best interests. In this respect, both Islamic and Western bioethics recognise that patient autonomy is not an absolute or predominant concept and is subject to limitations. There are accordingly both similar and different limitations between the Islamic and Western models with regard to the concept of autonomy, but they attend to the same purpose. Such limitations, instead of infringing the right of autonomy, serve to enhance the content and respect for patient autonomy by ensuring that it is guided and applied appropriately in

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Rathor et al, *supra*, n. 119 at p. 29.

consonance with other bioethical principles (in the case of Islamic bioethics, the governing principles of the *Sharī'ah*), leading to effective and sound decision making, and an overall improved healthcare environment. Medical decision making should not be a purely medical judgment but a combined opinion between the doctor and the patient. Autonomous medical choices are usually enhanced rather than undermined by a process of shared decision-making that is intrinsically valuable in modern medical practice.

