Importance of autonomy for medical ethics

Many ethicists such as *Sumner* [1], *Buchanan and Brock* [2]believe that autonomy is the most important of all principles for medical ethics.

Gillon [3]provides that autonomy should be regarded as the most important principle and whereby there is a clash with autonomy and the other principles, autonomy should be sovereign.

While the importance of autonomy to ethics and law is clear, what the principle of autonomy actually means is less so. *Gerald Dworkin* in his description of autonomy states:

It is equated with dignity…individuality, independence, responsibility, and self-knowledge. It is identified with qualities of self assertion, with critical reflection, with freedom from obligation…with knowledge of one's own interests[4].

Autonomy is argued to be a central tenant to the ethical argument within medical law[5]. *Glover* [6]states that patients should have the right to be allowed to make their own choices over what medical treatment they should receive. This allows for accountability and free will, with all the goods and burdens that it carries.

The principle of autonomy has its roots in traditional liberal philosophy, the basis for which may be summarised in *John Stuart Mill's* famous dictum that " over his own body and mind, the individual is sovereign"[7].

Autonomy maintains that it is never permissible for a doctor to give a patient treatment without the patient's consent, unless the patient is incompetent, or it may be necessary to avoid serious harm to others. In *Mill's* words " the

only purpose for which power can be rightfully exercised over any member… of a community, against his will, is to prevent harm to others”[8]. Thus, *Beauchamp and Childress* [9]demonstrate that capacity acts as a ‘ gate-keeper’ for the right of autonomy, determining whether said right will be respected in each individual case[10]. Even if the decision of the patient not to receive treatment seems perverse, it must be respected[11]. Thus the dominant view is that it confers a “ right to act on one’s own judgement about matters affecting one’s life, without interference by others”[12]. *Jennings* [13]and *Griffin* [14]highlight that autonomy refers to freedom of the will itself, and it relates to political freedom within a society, for us to act unencumbered by the interference of third parties for example doctors or essentially the State to matters concerning our own autonomy. This can be traced back to *Berlin’s* celebrated distinction between the concepts he labelled positive and negative liberty.[15]

At its most simple, autonomy denotes self-government[16]. Of course, determining what exactly this means can be seen as controversial. In this basic sense, it is an empirical question: we do not know *ex ante* that autonomy is good. Rather we ask whether it is good that people govern themselves, or to what extent they should do so. Autonomy raises concerns about what authority the ‘ self’ in a self governor has: for example, who is capable of autonomy? Can a child be autonomous? To what extent can an adult be allowed to self govern? Consideration of such matters has dominated the ethical debates within medical law.

It is important to note that the respect of autonomy does not mean that patients have the right to demand treatment, but to refuse treatment. In

Schloendorff v Society of New York Hospital [17], Cardozo J famously stated that:

Every human being of adult years and sound mind has a right to determine what shall be done with his own body[18]

This statement has come to encapsulate the consent requirement in modern healthcare. The principle of autonomy is particularly important when considering the legal requirement that a patient gives consent to treatment. In England and Wales, the General Medical Council[19]and the British Medical Association[20]both acknowledge the principle of autonomy and include a statement of the patient’s right to refuse treatment in their ethical guidelines. English medical law demands non-prejudicial deference to patients’ reasons in regards to allowing or refusing treatment, creating a practical system concerning moral value[21]. Whilst this is not intrinsically problematic, it creates problems in applying autonomy, which are often bound to ideas of rationality.

The law has further recognised the concept of patients’ rights by enacting the Human Rights Act 1998 incorporating Articles of the European Convention into domestic law. Society has also embraced the idea of patients’ rights in the form of the NHS Constitution. Once a person reaches the necessary conditions regarding age and capacity, medical treatment may be provided if the patient consents; consequently, the law strongly protects the right of a patient to refuse treatment. Before any treatment is given, the patient must, if found to be competent give consent. This must be based on the doctor or relevant medical profession having provided all the

necessary and sufficient information about the medical procedure, including the risks, benefits and alternatives that the patient can ultimately weigh up to arrive at an “ informed” decision.[22]

It is however clear that the law should protect, at least to some degree, patient autonomy[23]. We have Lord Sharman’s declaration that the issue concerned a patient’s “ fundamental human rights”[24]. Lords Bridge and Lord Templeman came to a compromise that there should be a standard defined by the medical profession which should be applied, subject to judicial oversight, which would create a more rigid and consistent system and respect for autonomy. Lord Diplock’s view was that ultimately it was for the patient to decide what should be done to her own body.[25]

As *O’Neill* writes, “ no themes have become more central…than the importance of respecting individuals’ rights and individual autonomy”[26].

The core problem in the right to autonomy is one that the courts have emphasised as the passing of information to the patient. Where medical professionals pass on the relevant information to the patient, but the doctor ignores the patients understanding of what they have been told[27]. A more explicit synthesis between information and the patient’s autonomy can be demonstrated in the case where autonomy was seen as most important, Chester[28]whereby the claimant had been advised surgery to the spinal column of her back, her consultant neurosurgeon, however, failed to disclose that the operation could worsen rather than improve her condition, even though he was under a duty to do so. The trial judge in his findings stated that the surgeon had not been negligent in the performance

of the operation, but his failure to warn her of the risks of the operation breached his duty of care to the patient. The decision in Chester has thus been hailed as a victory for autonomy[29].

Lord Bridge was of the same view, noting that any conscious adult patient of sound mind is to be entitled to decide for their own self whether or not they will submit to a particular course of treatment proposed to them[30]. This approach was however, abandoned by the Court of Appeal in the later bizarre decisions in Blyth[31]and Gold[32], but the original approach from *Chester* was resurrected subsequently by the courts.

An example of the principle of autonomy in practise is demonstrated in the following case; *St George's Healthcare NHS Trust v S* [33]whereby the Court of Appeal held that if a competent pregnant woman refuses to consent to medical intervention, it cannot be imposed upon her. This is so even if without said treatment the foetus will die. The right to refuse treatment was affirmed by the House of Lords in *Airedale NHS v Bland* [34] *.*

The context for this thesis is the law's response to the refusal of medical treatment by adult patients, whether these patients are capable, incapable, or covered by mental health legislation. In modem healthcare jurisprudence, the patient's right to refuse treatment has been consistently upheld as legally enforceable even if the refusal results in the patient's death[35]. The classic cases, through which the law in this area has developed, have involved articulate and strong-minded individuals who were guided by religious or other convictions in reaching the decision to refuse treatment, for example, a Jehovah's Witness may refuse a blood transfusion, believing

these procedures to be forbidden by the Bible[36]. In such cases, the principle of respect for autonomy supersedes competing principles such as the sanctity of life. Hoffmann LJ in *Airedale NHS Trust v Bland* [37]describes this as a “ strong feeling that there is an intrinsic value in human life, irrespective of whether it is valuable to the person concerned or indeed to anyone else.”

In the words of Lord Donaldson MR in *Re T* [38]a patient may choose to refuse treatment “ whether the reasons for making that choice are rational, irrational, unknown or even non-existent”. The right to decide one’s own fate is presupposed by a capacity to do so[39].

This autonomous approach conflicts with other ethical approaches such as that of virtue ethics. Virtue ethics emphasise that people should do the right thing and for the right reason. Hursthouse[40]suggests that a woman who decides to have an abortion so that her holiday plans are not interfered with is not acting in a good way, whereas a woman who has an abortion because she believes that the life of the child born would be intolerable, would be acting in a virtuous way. Under the right to autonomy, a person, whom has been deemed capable and has capacity, may chose to refuse treatment, even if it deems them to be not virtuous.

It is generally presume in law that adult patients have the capacity to make decisions. The test for capacity at common law is set out by the Court of Appeal in *Re T* [41] *.*

Although the issue of capacity was not central in *Re T* [42], Lord Donaldson MR made two important obiter contributions regarding the test for capacity.

First, his Lordship stated that a presumption of capacity applies to all adults[43]. Secondly, his Lordship stated that " the more serious the decision, the greater the capacity required."[44]

More recently, a statutory test has been introduced in Section 3(1) of the Mental Capacity Act 2005 (MCA). The MCA 2005 provides that a person is unable to make a decision if they are deemed unable to understand the information relevant to the decision, to retain the information, to communicate his decision, or to use or weigh the information as part of the process of making a decision[45]. Unlike the common law, the MCA does not expressly require a different level of capacity depending on the seriousness of the decision.

In both instances, the test for capacity centres on whether or not the patient has certain abilities directly related to the function of making a decision. Buchanan and Brock note, legal capacity is " a threshold concept, not a comparative one"[46]. As explained by Beauchamp, the legal capacity to do something is distinguishable from an individual's capacity in doing something[47]. Thus, the only consistent position within a legal framework based on the principle of autonomy is that the nature or consequences of the patient's decision is irrelevant if the patient has capacity.

The right of autonomy is restricted to capable patients only. All the evidence suggests that patients with mental disorders who refuse treatment in high-risk situations will be found incapable. There was no mechanism to deal with patients who wish to refuse treatment but who do not reach the designated

standard for capacity or to deal with the practicalities of administering treatment to incapable patients.

This is because the law's adherence to the autonomy paradigm has led it to neglect the need for a conceptual model within which to deal with patients without legal capacity[48]. For patients found incapable, until recently, there had been no adequate conceptual model within which to deal with the issue of treatment refusal. The law was content to leave the response to treatment refusal by incapable patients largely in the hands of the medical profession, limited only by a general and largely unrestrictive requirement that medical professionals act in the best interests of the patient[49]. Although the application of the capacity requirement clearly results in a rigid binary division between patients, the law failed to develop a model within which to deal with patients who were legally incapable but still wished to refuse treatment. This resulted in a change of the legal framework contained in the MCA, allowing a person, while capable, to make an advance healthcare decision either by conferring a lasting power of attorney on a donee[50]or by making an advance refusal of treatment. Section 24 of the MCA 2005 allows for a capable, adult person to make an advance decision to refuse specified treatment(s) in specified circumstances if he subsequently loses capacity.

Further, the human rights agenda set by the European Convention on Human Rights (the " ECHR") has had an impact on the legal response to healthcare decision-making in respect of incapable patients. In developing an appropriate model for incapable patients, the European Convention on Human Rights is of key importance. As all existing legislation must be interpreted and incorporated in a way which complies with the ECHR[51].

However, the Court's case law on this issue is ever developing, it is impossible to give an exhaustive overview on the position of the right to autonomy in the full protection of the ECHR, but personal autonomy can be seen to be closely linked with the broader concepts of human dignity; as demonstrated by Judge Martens in his dissenting opinion in 1990, that " man should be free to shape himself"[52]. This approach was confirmed by the Court in the *Pretty* judgement concerning the use of euthanasia (assisted suicide).

Although no previous case has been found to establish a right to self determination, also formerly known as the right to autonomy, being contained in any one particular article in the Convention, the Court considers that the notion of personal autonomy is an important principle which underlies the Convention guarantees in its interpretation.[53]

Judge Van Dijk phrased the right to autonomy as being considered a vital element of the ' inherent dignity', in which, according to the Preamble to the Universal Declaration of Human Rights, was set to constitute the foundations for freedom, peace and justice in the world throughout.[54]

However, the difficulty with the concept of autonomy under the ECHR is rather intangible. It cannot be considered as a right in itself as such rather than a parasite that attaches itself to the convention rights. The right to refuse treatment as protected under Article 8 has a scope beyond the right of autonomy. The Court recalls that even minor interferences are to be regarded as an interference with the right to respect for private life under Article 8, if it is carried out against the individual's will[55].

In *Sørensen and Rasmussen v. Denmark* , a case concerning freedom of association (Art 11 ECHR), the Court ruled that ‘ the notion of…autonomy is an important principle underlying the interpretation of the Convention guarantees’[56]. This often repeated, leaves room for discussion on whether personal autonomy underlies the interpretation of all Convention guarantees.

In addition to the protection afforded by Article 8, the right to refuse treatment may in some instances be protected by Article 3 of the ECHR, which contains an absolute prohibition on torture and on inhuman or degrading treatment. In *Herczegfalvy v Austria* [57]the ECHR found that treatment imposed against a patient’s will could, depending on the circumstances, be contrary to Article 3.

As the law stands, the only outlet for a court to make value judgements regarding the appropriateness of treatment refusal in a particular situation is through the application of the capacity requirement. In this way, the law relies on the capacity requirement so as to enable it to endorse a pure form of autonomy in difficult treatment refusal situations.

The role of autonomy in ethics has been criticised from a number of different perspectives. The most sustained critiques of modem autonomy have come from the communitarian perspective[58]. Feminist critiques also dispute the conception of the individual, rejecting “ moral subjects as autonomous”[59]. Feminist theorists also challenge the view of the autonomous or independent person as morally superior. Other critics argue that different cultures have different views and these may not fit within an individualistic autonomy based model[60]. Jennings argues that:

By normalizing and universalizing a particular set of cultural assumptions and privileged behaviours and a class-specific conception of rational moral choice, bioethics makes both a practical and an ethical mistake[61].

A number of commentators also challenge the presumption underpinning the autonomy principle that the autonomous individual is in a position to make a free choice. Wolpe argues that the idea of " free choice" is itself socially constructed and situated[62]and that a patient's freedom constellates on a number of structural factors that can add a coercive element to decision making such as those as burdening a family.

An overwhelming criticism demonstrated by many is should a patient be permitted to refuse consent to treatment even if this will mean a huge burden will be placed on the patient's family to care for them[63]. Schmitt argues that autonomy may only be achieved if others take on the burden of caring[64]. The courts have not yet considered the extent to which the interests of others justify limiting the right to refuse treatment. As noted above, it is consistent with liberal theory to interfere with an individual's autonomy in order to prevent harm to others[65]. A possible basis for such interference could arise in the context of contagious diseases[66]

To conclude, the idea that patients should be offered all the options and allowed to make voluntary choices about their own potentially life-changing health care is an important desire to prioritise patient autonomy. The ritualistic nature of autonomy is that a patient should be given a list of risks and then be allowed to make a decision based upon those risks has developed for good reason. Crucial to the respect of autonomy is the

fundamental principle which is increasingly recognised in ethical practise and by relevant human rights is that a person should have the ability to conduct their own life in a manner of their own choosing, without state interference, even if said decision is physically or morally harmful to said individual. It is important to note that Court's will only protect a persons' autonomy for the individual concerned, if harm or danger is imposed upon others then the Court will interfere.

It is appropriate that the long established principle of autonomy remains respected and significant within medical healthcare law, which has been demonstrated throughout this piece of writing, with acknowledgements to the criticisms of this principle.

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