### Chapter 1

# Autonomy, the Good Life, and Controversial Choices

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#### Introduction

Individuals have different values. They prioritize their values in different ways. Controversial choices are choices which are perceived by many to be either irrational or against a person's interests, such as engaging in harmful or excessively risky activities. When the medical profession is involved in such choices, the basic medical principle of acting in a person's best interests is challenged. Often doctors refuse to respect controversial choices on paternalistic grounds. We should all respect and facilitate the controversial choices of competent individuals, subject to resource limitations, our own and others' well-being and autonomy, and the public interest. But more importantly, sometimes such choices make for a better, more autonomous life. Sometimes, such choices reflect considerations of global well-being or altruism, or idiosyncratic attitudes to risk. Sometimes, they reflect unusual values. However, in some other cases, controversial choices are irrational and are not expressions of our autonomy. We have an obligation to make rational if controversial choices. I distinguish between Kantian and Millian conceptions of autonomy and the place of controversial choices within these. On both accounts, there is an important place for controversial choices in leading the autonomous life. Indeed, where rational, they should be encouraged as they increase the richness of the tapestry of human living, what Mill called "originality." Where irrational, we should aim to help people make better and more rational choices about their lives. Our controversial choices should be the result of decision and evaluation and capable of withstanding critical, normative challenge. Though at times destructive and corrosive, they can also be the essence of the good and selfconstructed life.

Consider the following examples of controversial choices.

#### Case 1 Sado-masochism

The appellants belonged to a group of sado-masochistic homosexuals who over a 10-year period willingly and enthusiastically participated in the commission of acts of violence against each other for the sexual pleasure engendered in the giving and receiving of pain. The group activities took place at different locations, including rooms equipped as torture chambers. Video cameras recorded the activities and tapes were copied and distributed among members. The activities included branding a victim with a wire heated with a metal blowlamp, use of a cat o'nine tails, and genital torture and violence to the buttocks, anus, penis, testicles, and nipples. All the activities were done with the consent of the passive partner or victim and were carried out in private. There was no permanent injury; no infection of wounds; no evidence of any medical attention being sought; and no complaint was made to the police, who discovered the activities by chance.

(R v. Brown, 1994)

In this case, the House of Lords ruled that the practice of sado-masochistic sexual activities constituted a crime, notwithstanding the consent of all parties involved. The grounds for interference in such choices is the public interest.

#### Case 2 Amputation for apotemnophilia

A Scottish surgeon, Mr Robert Smith, amputated the healthy legs of two patients suffering from apotemnophilia, a body dysmorphic disorder in which the patient feels incomplete with four limbs. The patients had received psychiatric and psychological treatment prior to the operation, but had failed to respond to these methods. Both operations were carried out privately and not publicly funded, and the patients were satisfied with the results. The NHS Trust responsible for the hospital banned further amputations (Dyer, 2000).

#### Case 3 Requests for "futile" medical treatment

Mr Leslie Burke was 45 years old. He had been diagnosed in 1982 with cerebellar ataxia, a degenerative brain disease. He was wheelchair-bound and his speech was affected, though his mental capacity was intact. Owing to the progressive nature of Mr Burke's disease, he would require artificial nutrition and hydration at some point. He sought a court ruling that artificial nutrition and hydration be provided if he became incompetent. Mr Burke sought a declaration that the rights enunciated in Articles 2, 3, 8 and 14 of the European Convention on Human Rights pursuant to the Human Rights Act 1998 (UK) were breached by the General Medical Council's guidance entitled, Withholding and Withdrawing Life-Prolonging Treatments: Good Practice in Decision-Making (R (Burke) v. The General Medical Council, 2004).

Justice Munby ruled in favor of Mr Burke, and declared that parts of the guidance were unlawful, as a competent person pursuant to Articles 3 and 8 is able to demand artificial nutrition and hydration in accordance with the rights of dignity and autonomy which enable a person to die in a manner in accordance with their desires.

However, the decision was appealed. The Court of Appeal ruled that Justice Munby erred in law. The Court of Appeal ruled that the guidance was lawful and that it did not contravene Articles 2, 3, or 8 of the Convention and set aside the six declarations made by Munby (*R (Burke) v. General Medical Council* (Official Solicitor and others intervening), 2005).

How far should people be allowed to pursue choices which are not judged to be in their best interests? The questions I want to ask are: Should these people act in such controversial ways? How should we act? How should we respond to people's controversial choices? The answer, I will argue, turns on how these people arrive at such controversial choices. People often have values which diverge from the dominant social values. These values lead them to make choices which are judged by some to be imprudent or irrational.

Controversial choices can be divided into three categories: refusal of assistance to which one has a legitimate entitlement, requests for assistance for enhancement or for assistance to which one does not have a clear legitimate entitlement, and requests for liberty to engage in activities which may result in future requests for assistance. These three categories overlap and map roughly onto the three more specific categories listed below.

#### Controversial Choices

Here are some examples of the three categories of controversial choice:

#### I Refusal of medical intervention

1.1 Refusal of medical intervention which is in the person's interests

Refusal of life-saving blood transfusion Refusal of life-saving cesarean section for obstructed labor

1.2 Refusal of medical intervention which is possibly in the person's interests

Some blood transfusions, for example, an elective blood transfusion following surgery where bleeding has been controlled and hemoglobin is stable Some tests, e.g. refusal of a blood test for diagnosis of a non-life-threatening condition, spinal tap for the exclusion of an unlikely cause of a headache, or painful nerve function test where treatments for the likely disorder have little effect

Interventions with non-demonstrated efficacy, e.g., surgical removal of advanced metastases

Interventions with little effect, e.g. chemotherapy for metastatic disease which extends life by a couple of months

#### 2 Requests for interventions<sup>2</sup>

2.1 Requests which appear to oppose a person's interests

Assisted suicide and euthanasia

Second best interventions:

General anaesthesia instead of local or regional anaesthesia, e.g., for a cesarean section

Antibiotic treatment for an inflamed appendix instead of appendectomy Useless interventions:

Antibiotics for a viral sore throat

Vitamin injections

2.2 Requests for enhancements, especially those with significant risk for the purposes of enhancement of normal features or some relatively worthless goal

Normal breasts made very large

Penis enlargement of a normal penis

Viagra for improved sexual performance in normal people

Amputation of a healthy limb

Extreme body modification

Laser eye surgery to achieve hawk-like vision

Sex change or body nullification

Artificial nutrition and hydration when permanently unconscious

# 3 Engaging in activities with a high risk of injury requiring medical intervention

Excessive dieting

Smoking

Using recreational drugs (alcohol, heroin, ecstasy, etc.)

Serving as a live organ donor (e.g., donating or selling two healthy kidneys)

Engaging in extremely risky sports (e.g., high-altitude mountaineering, extreme skiing, real fighting and, arguably, boxing)

Engaging in high-risk work (e.g., skyscraper construction, tunnel construction, coal mining, race-car driving, being a mercenary)

Risky sexual practices, e.g., "bare backing"

Passive risky lifestyles – gluttony, sloth, etc.

So that the discussion that follows includes a broad array of the kinds of cases listed above, I shall employ the term "humping" as the generic term for describing acting controversially. I stipulate "humping" to include all three categories of controversial action, although the examples in Category 1.1 could also be described as omissions.

The answer to the question of how we should respect controversial choices lies in whether people have good reasons for these choices, and how strong these reasons are. By "good reasons" I mean good normative reasons.

The critical question to ask when evaluating a person's choice to hump is to ask "Is there a good reason, in these circumstances, for that person to hump?"

A reason for acting is a fact or circumstance forming a sufficient motive to lead a person to act. Knowing a person's reasons allows us to understand why a person acted as he did. Imagine John has suffered a serious injury and would significantly benefit from a blood transfusion. He refuses. John's reason for refusing a blood transfusion is a desire to recover his health together with the belief that receiving a blood transfusion will cause AIDS. This reason explains why he acted as he did. It has been called an explanatory or motivating reason.

Good reasons for action are normative or justifying reasons for action. A reason for action is good if it meets a standard, that is, if it conforms to a set of norms governing that behavior. In one sense, John had a good reason to act as he did: if his beliefs were true, not receiving blood would be an effective way of avoiding AIDS. If the blood transfusion was not essential, this would be a rational course of action.

However, John's action is based on an irrational belief. The chances of his contracting HIV from a blood transfusion are very very low. He is more likely to recover his health by having a transfusion. Overall, he has most reason to accept a blood transfusion. While he has a motivating reason to refuse a transfusion, he has no good reason to refuse a blood transfusion.

#### Kinds of Normative Reasons for Action

There are different kinds of normative reasons for action. Two kinds of reasons frequently account for or are relevant to controversial choices: prudential reasons and moral reasons.

#### Prudential reasons

Prudential reasons are reasons to do with a person's well-being or best interests. Prudential reasons can constitute good reasons for action. Indeed, medical practice is currently based on a principle of offering interventions which are in a person's best health or medical interests. The *Burke* case illustrates the principle

that doctors are only obliged to provide treatments which are in the best interests of the patient.

In many cases, whether there is a good reason to hump turns on whether there is a prudential reason to hump. There are many points at which a doctor and patient may disagree about whether there is a prudential reason (that is, whether an intervention is in the patient's best interests) for some action.

#### Three theories of well-being

There are three main theories of well-being. Many modern philosophers advocate a combination of all three theories, on the grounds that each highlights relevant values not captured by the other two.

#### Mental state or hedonistic theories

Hedonistic theories of well-being are defined in terms of mental states. The simplest view is that happiness, or pleasure (understood broadly as a mental state) is the only intrinsic good and unhappiness or pain the only intrinsic bad. More complex views include a greater plurality of states of mind as contributing to well-being. Freud is reputed to have refused analgesia when dying of cancer, although in pain, on the grounds that he preferred to think in torment than not to be able to think clearly (cited by Griffin, 1986).

A central issue for pluralistic accounts is which mental states are to be included in an account of well-being. Two types of answer have been given: one is *preference hedonism* (or subjective hedonism) in which the valuable mental states are those that are desired. Sidgwick wrote:

I propose therefore to define Pleasure . . . as a feeling which, when experienced by intelligent beings, is at least implicitly apprehended as desirable, or – in cases of comparison – preferable.

(Sidgwick, 1963 p. 127)

The second way in which mental states might be ascribed a value is to propose that some mental states are objectively valuable. Objectively valuable mental states might include fulfillment, calm, peace, hope, the experience of love and friendship, happiness, and a sense of achievement. Each of the main alternate theories of well-being picks up on one of these ideas.

On hedonistic theories, the pleasure or happiness that we derive from some risky activity is a strong reason for action.

#### Desire fulfillment theories

According to desire fulfillment theories, well-being consists in having one's desires fulfilled. These theories give weight to individual values and they account well

for the plurality of values. Economic theory commonly employs a related notion of value, and such accounts are widespread in philosophy and the social sciences in general. On the most plausible desire fulfillment theories, desires should be informed (of the relevant facts) and freely formed to count towards our well-being.

A strong, informed desire to engage in some harmful or risky activity grounds a prudential reason, on this account of well-being.

#### Objective list theories

According to objective list theories of well-being (sometimes called substantive good or perfectionistic theories) certain things can be good or bad for a person and can contribute to well-being, whether or not they are desired and whether or not they lead to a "pleasurable" mental state. Examples of the kinds of things that have been given as intrinsically good in this way are gaining knowledge, having deep personal relationships, rational activity and the development of one's abilities. Examples of things that are bad might include being betrayed or deceived, or gaining pleasure from cruelty. High-altitude mountaineering, though extremely risky, might provide great objective achievements which ground a reason to take the risks.

#### Composite theories

Each of the three theories of well-being outlined above seems to identify something of importance but all have problems. Because of this many philosophers opt for a composite theory in which well-being is seen as requiring aspects of all the theories. Well-being is constituted by engaging in objectively worthwhile activities which we desire and which provide us with pleasure.

These three theories and the composite theory have some practical implications for controversial choices.

#### Implication 1 Health v. other components of well-being

The first point to note is that our well-being includes much more than our health. Indeed, arguably, health is an instrumental good which facilitates our engagement in worthwhile activity that we desire and which gives us pleasure. Cancer is bad because it stops us from completing our projects, seeing our children grow, doing what we planned with our partner, and so on. A symptomless disease, which does not affect length or quality of life, is of no practical importance.

Whereas doctors may be concerned to promote health, patients may be concerned to promote their well-being more globally conceived. Thus, the fact that not humping is healthier does not settle the question for the potential humper of whether there is good reason to hump. Indeed the (apparent) problem of risky activity (Category 3), such as masochism, is that people trade health for other components of well-being, like pleasure. Enhancements are often sought by people at

the expense of risk to their health to improve their well-being in other ways (Category 2). Apotemnophilia is classified as a psychiatric disorder. But equally, it could be seen as an example of people believing they are better off without their limbs. Amputation of healthy legs (Dyer, 2000) is not in a person's best medical interests in terms of physical health. But if the person will be depressed and psychologically dysfunctional with two legs, and there is nothing you can do about that, then amputation may be justified because of the improvement in their global well-being that will result (Fisher and Smith, 2000), even without classifying it as a disease, though classification as a psychiatric disease facilitates the deployment of medical resources.

While a person may have good reason to hump, even if humping is unhealthy, doctors might believe they *qua* doctors should not facilitate unhealthy humping. Should health or well-being be the primary goal of medicine? This is a difficult question to answer. It may be that the primary goal of a health service should be health and not well-being. The reason for this may be that by concentrating on the local goal of health, services can be most efficiently deployed. Specialization may be the most cost-effective use of resources.

Even if this argument is correct (and it is not clear that it is correct), it will not rule out respecting many controversial choices. Refusal of medical care involves forgoing medical services. There is a well established legal right of patients to refuse medical treatment, even life-saving medical treatment (*In Re T* (Adult: Refusal of Treatment), 1993). By the same principles, we should all allow people to act in controversial ways. Engaging in risky activities does not immediately involve use of medical resources.

#### Implication 2 Differences in conceptions of the good and estimations of risk

According to decision theoretic consequentialism, we have a prudential reason to choose a course of action when that action maximizes our own expected value. In general terms, the expected value of adopting any course of action can be given by:

Probability (good outcome given that course taken) × Value (good outcome) + Probability (other outcomes given that course taken) × Value (other outcomes)

#### Consequentialism instructs the agent to:

- 1 list all the relevant possible courses of action
- 2 list the possible outcomes of each action (this strictly includes *all* possible outcomes or consequences that stem from this action, no matter how far in the future)
- 3 estimate the probability that each outcome of each action will occur, given that the action in question is taken
- 4 assign values to each possible outcome

- 5 calculate the expected value of each possible outcome. This is the product of the value of that outcome and the probability of it eventuating, given that a particular action is taken
- 6 calculate the expected value of each action. This is the sum of expected values of each of the possible outcomes (or consequences) of that action
- 7 choose the action with the greatest expected value.

Given the different ways of conceptualizing the good or what is of value, there will be legitimate disputes about which course of action maximizes expected value. On more objective conceptions there will be a greater divergence between our autonomous choices and what is best for us. On desire fulfillment theories, what we desire defines our good, at least in terms of our informed desires. For example, it can be rational for a person to engage in risky sexual or sporting practice if she accords greater value to sex or sport than most of us and that value is justifiable.

In a world of incomplete information, apparently irrational choices may reflect different probability estimations, as well as different value estimations. I fractured my leg badly, rupturing the artery to my leg and developing a compartment syndrome. My hemoglobin dropped to about 5. The normal is 14–18 g/dL. This is severe anemia – death may occur around 3. Transfusion is normally performed when the hemoglobin falls below 8. Because my bleeding had ceased, the ruptured artery was repaired and I was stable, I did not want a blood transfusion. I made a judgment that I did not want to incur the risks of transfusion. Although these are small, they are present. There are transmissible agents which cannot be tested for. There is also the possibility of error in testing or in giving blood. There was surprisingly little evidence as to the risks of blood transfusion or to the chances it would benefit me in this situation. Having spoken to a number of experts, my rational estimate was that the risks were not worth taking; most doctors disagreed (Savulescu, 2003).

#### True imprudence

There will be cases of true imprudence which are not disputes about the value of non-health-related well-being, different conceptions of the good, or different weighting of risk. Instances of true imprudence may be fewer on some desire-fulfillment conceptions of well-being. For example, on the most basic conception of desire-fulfillment theory, the informed desire account, a person who knows all the relevant facts and most wants to hump consequently has most reason to hump. However, more plausible accounts take into consideration not merely satisfaction of present desires, but also future desires. On such global theories, the harm and frustration of future desires are relevant. Examples of true imprudence include dying for the sake of natural childbirth, dying for the sake of a (likely false)

belief that God forbids the taking of blood, and refusal to act on information about smoking. Typically, truly imprudent choices result from weakness of will or a complete absence of evaluation of the activity concerned. The person who drunkenly has unprotected intercourse, for no other reason than he has lost all control of desire, acts imprudently.

Some apparently imprudent choices reflect a rational process of according value to non-health-related well-being or different but justifiable conceptions of the good or estimates of risk. But how should we evaluate truly imprudent controversial choices?

#### Kantian autonomy and controversial choice

The right of a patient either to consent to or to refuse medical treatment (and more generally the right of persons to exercise free choice) is grounded in the long-established principle of respect for autonomy, that is, the right to selfdetermination (Beauchamp and Childress, 1989). The legal validity of consent to treatment rests on those elements necessary to establish the patient's competence to make autonomous choices: broadly, provision of information regarding the treatment, understanding of such information, and the ability to appreciate the consequences of decisions regarding treatment (see Brazier, 1987, pp. 121-5). Similarly, the test in English law as to whether a patient is capable of validly refusing treatment requires only that they possess (and can utilize in the decision-making process) sufficient information regarding the "nature, purpose and effects" of the proposed treatment (Re C (Adult: Refusal of Treatment), 1994). Subject to this, the patient has an "absolute right to choose." This right is upheld in law "notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent" (In Re T (Adult: Refusal of Treatment), 1993), a principle that has been reiterated a number of times (Re C (Adult: Refusal of Treatment), 1994; (*Re MB* (Caesarean Section), 1997).

This implies that others – neighbors, friends, counselors, family – should respect the final choices of competent individuals. It also implies that there is a requirement to ensure that people making controversial choices are competent to make such decisions.

Importantly, whether an individual's decision is ultimately respected (by doctors, family, and friends) turns on whether that individual is competent or incompetent, and sufficiently informed of the consequences of the decision, not on whether the decision is rational or irrational. Thus whether doctors should amputate a healthy limb, or whether advance directives to provide artificial nutrition in persistent vegetative states should be respected, turns on whether the individual is competent, not whether he/she is rational. (There are limits related to distributive justice, harm to others and the public interest which I briefly discuss below.)

However, we must distinguish between a decision made by a competent

person and a fully autonomous decision. According to the German philosopher, Immanuel Kant, our autonomy is tied to our rational nature (Kant, 1964). What separates human beings from other animals is rationality and the capacity to act on the basis of normative reasons. Choice is an expression of autonomy, on a Kantian conception, only when it is rational.

There are compelling independent ethical arguments to suggest that the exercise of full autonomy requires some element of rationality in addition to those elements of information and understanding identified by the courts (Harris, 1985; Savulescu and Momeyer, 1997). These arguments are based on the concept of self-determination. The idea of self-determination is not mere choice but an evaluative choice of which of the available courses of actions is better or best. The reason that information is important is to enable an understanding of the true nature of the actions in question and their consequences. But if information is important, so too is a degree of at least theoretical rationality to draw correct inferences from these facts and to fully appreciate the nature of the options on offer. More importantly, fully autonomous action reflects normative deliberation about the value of the choices on offer. We must not merely consider the relevant facts about the nature of the consequences of the actions on offer, but the value of these states of affairs.

We should therefore distinguish between two kinds of true imprudence:

#### Moral reasons and rational imprudence

Rational imprudence is imprudence based on a proper and rational appreciation of all the relevant information and reasonable normative deliberation. Some other reason grounds the action beside prudence – this is typically the welfare of others. Thus we should respect decisions to donate organs or participate in risky research, if these are based on a proper appreciation of the facts. However, merely citing a normative reason is not sufficient to make some action, all things considered, rationally defensible. To donate one's healthy kidney to a sick relative would not be rationally defensible if the chances of rejection were very high. There must be a reasonable appreciation of the values in question.<sup>3</sup>

#### Irrational imprudence

Irrational imprudence is imprudence where there are no good overall reasons to engage in the imprudent behavior. The explanation might be that the person is not thinking clearly about information at hand or holds mistaken values or wildly inaccurate estimates of risk. We should attempt to reason with and try to dissuade the irrationally imprudent.<sup>4</sup>

The appropriate response to irrational imprudence is not paternalism but an attempt not merely to provide information but to facilitate the proper reasoning about that information. More importantly it may require challenging a person's values and the reasons for holding those values (Savulescu, 1995). As individuals, we must try to construct coherent defensible lives according to what we judge as best. We discover such lives by being challenged in our values and by defending them. To achieve full autonomy, we require normative dialogue with others.

Sometimes, a case is made that where "an autonomy interest is minimal and a medical benefit maximal," paternalistic intervention can be justified (Beauchamp, 2003). Medical practice nowadays tends towards the incorporation of rationality as a criterion for respecting patient choice (see, for example, American Psychiatric Association, 1998; Del Carmen and Joffe, 2005) even if recent legal decisions have not done so. While it may be the case that "[i]n modern law medical paternalism no longer rules," (*Chester v. Afshar*, 2005), based on a principle of respecting the choices of competent persons, a richer construction of the concept of autonomy of the person is in order (Stauch, 1995), and greater concern to promote greater understanding and normative dialogue between doctors and patients.

I have argued that to be truly autonomous, one must strive to act on the basis of reasons, to strive to be rational. Whether a choice to hump is fully autonomous turns on the reasons that individual has in the particular circumstances. While there may be reasons in general not to hump, an individual may have most reason to hump, given a particular history and set of circumstances.

Consider, for example, the controversy over amputation of healthy limbs. Bioethicists Bayne and Levy (2005) argue that an alternative explanation of the request for amputation is not that it is a psychosexual disorder (apotemnophilia) involving sexual attraction to amputees, but it represents "a mismatch between their body and their body as they experience it," or Body Integrity Identity Disorder. They argue that this condition is poorly studied and treatments for it are typically ineffective. Individuals are often driven to destructive and dangerous practices (such as self-amputation by placing the limb over a rail track). When no other more effective treatments are available, surgeons ought to be permitted, they argue, to amputate such healthy limbs (ibid.).

Wesley J. Smith responded: "That this kind of article is published in a respectable philosophical journal tells us how very radical and pathologically non-judgmental the bioethics movement is becoming" (Smith, 2005).

However, I believe Bayne and Levy's conclusions are rather timid. A stronger conclusion is possible. It may be that some individuals, given their psychology, upbringing, and circumstances, will not respond to any other less invasive measures. Such individuals might have *most reason* to seek amputation. Thus not only might amputation be permissible in some situations, it might be desirable. While it is a tragedy for nearly all of us to lose a limb, there might be good reasons for certain rare individuals to choose this fate. We must be open to such radical possibilities.

#### Millian autonomy

There is another conception of autonomy which, while it gives consideration to reason, accords more weight to the exercise of choice. The British philosopher John Stuart Mill was the most famous proponent of autonomy, or as he called it, individuality. He was also a strong advocate of originality.

I have said that it is important to give the freest scope possible to uncustomary things, in order that it may appear in time which of these *are fit to be converted into customs*. But independence of action, and disregard of custom, are not solely deserving of encouragement for the chance they afford that better modes of action, and customs more worthy of general adoption, may be struck out; nor is it only persons of decided mental superiority who have a just claim to carry on their lives in their own way. There is no reason that all human existence should be constructed on some one or small number of patterns. If a person possesses any tolerable amount of common sense and experience, his own mode of laying out his existence is the best, not because it is the best in itself, but because it is his own mode.

(Mill, 1910, p. 125)

What Mill means here is "his own *chosen* mode" of existence. A true commitment to freedom implies supporting people's "original" choices. Indeed, there is value, on Mill's argument, just in making one's choices. Madder has described this as "existential autonomy" (Madder, 1997). Sometimes those active choices or decisions will be not to act. But on this account, there is value to decision and choice, even an active decision not to act. What subverts autonomy is laziness and passive acceptance. In this way, those who make controversial choices may be more autonomous than the herd that passively and unreflectively live their lives according to custom.

He who lets the world, or his own portion of it, choose his plan of life for him, has no need of any other faculty than the ape-like one of imitation. He who chooses his plan for himself, employs all his faculties. He must use observation to see, reasoning and judgment to foresee, activity to gather materials for decision, discrimination to decide, and when he has decided, firmness and self-control to hold to his deliberate decision . . . It is possible that he might be guided in some good path, and kept out of harm's way, without any of these things. But what will be his comparative worth as a human being? It really is of importance, not only what men do, but what manner of men they are that do it. Among the works of man, which human life is rightly employed in perfecting and beautifying, the first in importance is surely man himself.

(Mill, 1910, p. 117)

Individuality is the same thing with development, and . . . it is only the cultivation of individuality which produces, or can produce, well-developed humans.

(Ibid., p. 121)

This quote comes from the chapter from *On Liberty* entitled, "Of Individuality, as One of the Elements of Well-being." Mill clearly believes that individuality is one of the goods of life. The value of individuality for Mill is intrinsic. For although a person may "be guided in some good path," that is, achieve good, something very important will be lacking: that life will not be his own. Mill elsewhere criticizes subjugation of oneself to custom and fashion, indifference to individuality and lack of originality (Mill, 1910, pp. 119–20, 123).

On a Kantian account, a controversial choice promotes autonomy if there are good normative reasons for that choice. On a Millian account, controversial choices are valuable insofar as they promote a better life, a life of more well-being. But they are also independently valuable when they are expressions of active decision and deliberation about one's life and how to live. There is a value in just deciding to be.

#### Limits on Respect for Autonomy

There are limits on the exercise of autonomy, whether prudent or imprudent, rational or irrational.

#### Distributive justice

Distributive justice requires that our limited medical resources be allocated fairly (Wikler, 1978; Veatch, 1980; *R v. North West Lancashire HA Ex p A*, 2000). Doctors can legitimately disconnect a person who has a very poor prognosis from a ventilator, even though that patient was expecting a miracle, if a better prognosis patient requires the ventilator. The cost of providing artificial nutrition and hydration, and the use of those resources for other patients with better quality of life, provide a reason to withhold life-prolonging artificial nutrition and hydration. Such reasons provide limits on how others – friends, family, and others – should respond to controversial choice.

#### Harm to others

On Mill's liberalism, two "maxims" determine the limits of state interference in individual action:

The maxims are, first, that the individual is not accountable to society for his actions, in so far as these concern the interests of no person but himself. Advice, instruction, persuasion, and avoidance by other people if thought necessary by them for their own good, are the only measures by which society can justifiably express its dislike or dis-

approbation of his conduct. Secondly, that for such actions as are prejudicial to the interests of others, the individual is accountable, and may be subjected either to social or legal punishment, if society is of opinion that the one or the other is requisite for its protection.

(Mill, 1900, pp. 150–1)

Harm to others may take many forms. The psychological harm to doctors from performing euthanasia is one reason against it. The increase of a tendency to violence by refusing to take some medication or by taking some drug are strong reasons for coercion.

There have been many cases where pregnant women have been incarcerated for engaging in behavior dangerous to their fetus. Some competent women have been forced to undergo cesarean sections for the sake of their fetus. Such decisions have been widely criticized on the basis of a woman's right to control her own body and the lower moral status which a fetus has in law (*Re S* (Adult: Refusal of Treatment), 1993; *Re MB* (Caesarean Section), 1997; *St George's Healthcare NHS Trust v. S*, 1998; Crafter, 1994; Draper, 1996; Cahill, 1999). However, where a fetus will survive in a damaged state, there is a reason to intervene in dangerous maternal behavior not for the sake of saving the fetus's life, but on the basis of preventing harm to a future individual (Savulescu, forthcoming (a)).

#### Public interest

There are other public interest considerations, such as those cited in the case of sado-masochism that may justify interfering in individual liberty or failing to facilitate autonomy. The archaic crime of maim is one example:

A maim was bodily harm whereby a man was deprived of the use of any member of his body which he needed to use in order to fight but a bodily injury was not a maim merely because it was a disfigurement. The act of maim was unlawful because the King was deprived of the services of an able-bodied citizen for the defence of the realm.

(R v. Brown, 1994, at p. 47)

However, in a liberal state with a commitment to autonomy and freedom, public interest should only be invoked in most unusual circumstances. We no longer have kings who need human fodder to be slaughtered in some irrational defense of the realm. Morally, it is hard to see the basis for interfering in consensual sadomasochism.

Indeed, while doctors may not be under a *legal* obligation to provide what are claimed by others to be "futile" treatments, there is a moral reason for them to offer such treatments in some circumstances. Leslie Burke's conception of his own best interests diverged from those of his doctors. Burke preferred artificial nutrition and hydration at the end of life. Some people accord value to being kept alive

in a permanently unconscious state, even when doctors and courts (*Airedale NHS Trust v. Bland* [1993]) judge that it is of no benefit. Others prefer to be kept alive in marginal states, hoping for a miracle. The liberal commitment to enable people to form and act upon their own conception of a good life provides a moral provision for providing such interventions.

#### Children and Controversial Choice

Parents make all sorts of controversial choices about their children and we give considerable freedom to parents (Wikler, 1978) bringing up their children. Examples include:

- health habits (e.g., diet, work, training, sleep, hobbies, exercise, etc.)
- risk exposure (e.g., sports, such as motocross, horse riding, off-piste skiing, bush walking, etc.)
- culture (e.g., vegan diet, circumcision, body piercing, tattooing).

It is clear that parents, doctors, and others must act in incompetent children's best interests, based on a plausible and defensible account of those interests, even when those interests diverge from parental values (Gillick v. West Norfolk and Wisbech Area Health Authority, 1986; Re R (A Minor) (Wardship: Consent to Treatment), 1991; Secretary, Department of Health and Community Services v. JWB and SMB (Marion's case), 1992; Re W (A Minor) (Medical Treatment: Court's Jurisdiction), 1993; Royal Alexandra Hospital for Children Trading as Children's Hospital at Westmead v. J and Ors, 2005; McLean, 2000).

When parents make controversial choices for their children, these choices must meet higher standards before they are respected (Savulescu, forthcoming(b)):

- 1 It must be *safe* enough, compared to other interventions children are exposed to.
- 2 The parent's choices must be based on a *plausible conception of well-being* and a better life for the child and not on some idiosyncratic, unjustifiable conception of the good life. In addition, the choice must be based on a good enough expectation of realizing a good life. For this reason, while competent adults can refuse life-saving blood transfusions for themselves, parents cannot refuse life-saving blood transfusions for their children on any grounds.
- 3 It must be consistent with development of autonomy and a reasonable range of future life plans for the child. For example, while adults may be allowed and even have good reason to have one of their healthy limbs amputated, parents could never have the healthy limb of their child amputated for many reasons, including the fact that it removes a range of possible good futures from the child's grasp. Female circumcision, and the removal of an organ of female

sexual pleasure, severely constrain the range of possible good lives for that child, stunting the possibility of full sexual satisfaction. It should not be permitted. Male circumcision is different precisely because the possible consequences are more mixed and more uncertain. The reasons for accepting male circumcision include social and cultural considerations, as well as medical considerations such as reduced risk of disease (e.g., penile cancer) and infection (e.g., HIV and HPV). The reasons against accepting the parental choice include the possibility of surgical mishap and reduced penile sensation (see Short, 2004; Hutson, 2004; and Viens, 2004).

#### Controversial Choices and the Duty to Strive Toward Perfection and Full Autonomy

When faced with some choice to engage in some controversial activity which I have called humping, we should ask: "Is there a good reason, in these circumstances, for that person to hump?"

The controversial choices of competent individuals should be respected. But, at the same time, we each have a duty to be better and to make our decisions with thought and care. Physicians and public policy can promote the achievement of this goal through rational engagement (Savulescu, 2001; 2002) and not through coercion or denial of the only means for competent people to express their conceptions of the good life.

For example, requests for what is judged to be futile medical care may be denied outright on the grounds of justice and scarcity of resources, but where there are no relevant considerations of distributive justice, then doctors have an obligation to engage with patients requesting such care and examine their reasons for such care. In some circumstances, such care may be central to their conception of the good life and there would be reasons to provide it. Similarly, refusal of beneficial medical care, such as life-saving transfusions or important diagnostic tests, should be addressed through rational engagement seeking to understand the reasons for refusal and the relation of that choice to the patient's conception of a good life for himself or herself. Doctors should try to persuade patients to revise their conceptions of the good life or their choices in relation to their conceptions, but they must also be open to the possibility of radical and justifiable diversity in plausible conceptions of the good life.

As persons, we should aim to lead autonomous lives, to be individuals. On a Kantian conception, to be an individual is to respond to the circumstances and to act on the basis of reasons. But reasons pertain to different individuals at different times and in different circumstances. We must exercise our practical judgment in deciding what we have most reason to do in these particular circumstances. For some people who request amputation of a healthy limb, there may be no better alternative at this point in time. If they have failed any attempt at psychological

readjustment, there may be good reasons to accede to their requests. Similarly for requests for cosmetic and body modification. Not everything goes. But we must answer the question: what is there good reason for me or this person to do, given history, the nature of the person and the particular set of circumstances at this time. It may be wrong for one person to have her breasts enlarged, because it will not bring her what she wants; however, another may have very good reason to enlarge her breasts and may be entirely happy with the result.

There can be very good reasons for engaging in risky or harmful activity. I remember a television documentary on a man who donated one of his kidneys to his son with kidney failure owing to the inherited condition Alport's syndrome. His second son also had kidney failure because of the same condition and a cadaveric kidney could not be found. He wanted to donate his remaining kidney to his second son so the son could live without the burden of dialysis. His justification for imposing dialysis on himself was that his life was over and his son's life was still ahead of him. Surgeons refused to remove his healthy remaining kidney and transplant it to his son. I believe there may have been good reasons to support this man's choice and, if the chances of his son obtaining a satisfactory result were high, good reason to provide the procedure.

On a Millian conception of autonomy, or existential autonomy, there is value in active choice, in originality. Not only should we be allowed or facilitated in forming and acting on our own conception of the good life, we have an obligation, rational and moral, to form and act on our own conception of the good life. A life is like a work of art. We should not forge a counterfeit, but rather aim to construct our own masterpiece, or at least our own creation. Active choice, commitment to one's own goals, perserverance, a sense of excellence and a vision are the ingredients of the self-constructed life. Controversial or different choices, far from being alien to self-constructed life, are an important ingredient, often recognized later as genius. We should not fear the different or distant, but be prepared to embrace it.

Life involves risk. Many of the greatest lives have involved the greatest sacrifices. The fact that an activity or lifestyle involves risk to health is only one reason against it. It is important, especially from a Millian perspective, to consider how risky activity is central to a self-constructed conception of the good life. Many people seek risk and the activities associated with risk bring the greatest rewards. Risky work or sporting activities may be central to the development of a sense of identity. While in general there appear to be good overall reasons not to smoke or take harmful recreational drugs, in certain doses and in certain circumstances, such activities may play a defensible part of a good life. Smoking a pipe in one's library while reading after dinner may provide enough pleasure to justify the risk. Similarly, occasional use of marijuana or other recreational drugs may be defensible in the context of a certain conception of a good life. After all, alcohol has established its place as a legitimate part of a reasonable conception of the good life. Some people abuse alcohol, but many use it in a way which they rationally believe makes their lives go better.

When doctors or others disagree with people's values or probability estimates,

they should reason with them and engage them in normative dialogue. But if the patient is competent, the best reasons for not respecting their choices are not that the choice is imprudent or irrational, but on the basis of justice considerations and the fair allocation of medical resources, or on the basis of harm to others. The importance of freedom to construct our own conception of the good life, and to act on it, requires that doctors respect irrational choices, and, where resources allow, facilitate the originality and diversity of human existence.

I must live my life according to what I think is good, not according to what others think is good.

#### Acknowledgments

Thanks to Sarah Chan for invaluable assistance and to the 21st Century School Seminar Group, Philosophy Faculty, University of Oxford, for helpful comments. The Uehiro Chair in Practical Ethics and the Oxford Uehiro Centre for Practical Ethics are supported by the Uehiro Foundation on Ethics and Education.

#### Notes

- 1 This is a queston of justifiable coercion and how far society respects personal autonomy, the subject of this volume's section on liberty.
- 2 The topics in Category 2 are discussed further in Chapters 4–10 of this volume's section on decisions of physicians and other health professionals.
- 3 Some people would not describe altruistic self-sacrifice as imprudent. I am using the term imprudence to include all acts which are against self-interest, including altruism.
- 4 If they are incompetent, the law allows their choices to be overridden.

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