

# Autonomy in medical ethics after O'Neill

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*J Med Ethics* 2005;31:127–130. doi: 10.1136/jme.2004.008292

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Received 31 January 2004  
In revised form  
25 April 2004  
Accepted for publication  
27 May 2004

Following the influential Gifford and Reith lectures by Onora O'Neill, this paper explores further the paradigm of individual autonomy which has been so dominant in bioethics until recently and concurs that it is an aberrant application and that conceptions of individual autonomy cannot provide a sufficient and convincing starting point for ethics within medical practice. We suggest that revision of the operational definition of patient autonomy is required for the twenty first century. We follow O'Neill in recommending a principled version of patient autonomy, which for us involves the provision of sufficient and understandable information and space for patients, who have the capacity to make a settled choice about medical interventions on themselves, to do so responsibly in a manner considerate to others. We test it against the patient–doctor relationship in which each fully respects the autonomy of the other based on an unspoken covenant and bilateral trust between the doctor and patient. Indeed we consider that the dominance of the individual autonomy paradigm harmed that relationship. Although it seems to eliminate any residue of medical paternalism we suggest that it has tended to replace it with an equally (or possibly even more) unacceptable bioethical paternalism. In addition it may, for example, lead some doctors to consider mistakenly that unthinking acquiescence to a requested intervention against their clinical judgement is honouring “patient autonomy” when it is, in fact, abrogation of their duty as doctors.

We live in the “time of the triumph of autonomy in bioethics” in which “the law and ethics of medicine are dominated by one paradigm—the autonomy of the patient”.<sup>1</sup> This is, perhaps, not surprising given that “from the outset, the conceptual framework of bioethics has accorded paramount status to the value-complex of individualism, underscoring the principles of individual rights, autonomy, self-determination and their legal expression in the jurisprudential notion of privacy”.<sup>2</sup> These were the weapons required to attack and breach the citadel of medical paternalism that dominated the patient–doctor relationship until at least the middle of the twentieth century. One influential medical sociologist has argued that there is an important link between the “triumph of autonomy in American bioethics” and American individualistic culture more generally.<sup>3</sup> However, there are growing indications that a number of bioethicists are becoming less than comfortable with this individualism.<sup>4</sup> In this article we wish to argue that the individualistic paradigm of “autonomy” is an aberrant application and we wish to address the question, “How are we to understand ‘autonomy’ in medical ethics after Onora O'Neill's challenging Gifford<sup>5</sup> and Reith lectures?”<sup>6</sup>

Much writing on the subject of autonomy fails to define the term and the way the authors are using it.<sup>7</sup> Understood literally “autonomy” is self-governance or self-determination. Although originally applied by the ancient Greeks to city-states, philosophers extended the concept to people from the eighteenth century onwards. Kant, in particular, gave autonomy a central place and there it has remained. What has changed is the interpretation of “autonomy”. O'Neill<sup>8</sup> believes that it has now become too individualistic. She reminds us that John Stuart Mill “hardly ever uses the word, autonomy” and when he does so refers to states rather than individuals. “Mill's version of autonomy”, she asserts, “sees individuals not merely as choosing to implement whatever desires they happen to have at a given moment, but as taking charge of those desires, as reflecting on and selecting among them in distinctive ways.”<sup>9</sup> She also maintains that Kant never speaks of autonomous people or individuals and “he does not equate it with any distinctive form of personal

independence or self-expression”. She continues, “Kantian autonomy is manifested in a life in which duties are met, in which there is a respect for others and their rights”. Kant's view of autonomy is not “a form of self expression”, but “rather a matter of acting on certain sorts of principles, and specifically on principles of obligation”. Thus in Kant's account of moral autonomy “there can be no possibility of freedom for any one individual if that person acts without reference to all other moral agents”.<sup>8</sup> O'Neill entitles this “principled autonomy” (which we will contrast with “individualistic autonomy”). According to Jennings,<sup>9</sup> Kant and others established that “morality requires a person to assume responsibility for his or her choices, actions and decisions and to act on the basis of informed reason and autonomously held, principled commitments. Others in turn must respect the moral agency and reasonable commitments of the person in this sense.”

Individualism has, of course, honourable origins in the humanism of the Renaissance, the rationality of the Enlightenment and the struggle for personal and political freedom out of which our Western democracies sprang. However, in the late twentieth century, this led to the operational concept that each of us carries our own “quantum” of ethics—“I have my ethics; you have yours and neither should impinge on the other”. It also means that “rights” now tend to be claimed without any sense of reciprocal obligations and that “rights are multiplied, assumed or attributed where they do not exist, replacing the language of duties which oblige even where there are no rights”.<sup>10</sup> In the opinion of Schneider,<sup>1</sup> “The overwhelming weight of bioethical opinion endorses not just the autonomy principle, but a potent version of it”. He considers that this paradigm is sustained by the “assumption that autonomy is what people primarily and pervasively want and need”. Thus the dominant view of individualistic autonomy in much recent liberal bioethics (and more generally in Western society) is that it confers a “right to act on one's own judgment about matters affecting one's life, *without interference by others*”<sup>10</sup> (our italics). Following O'Neill, we believe that this individualistic version of autonomous choice is

fundamentally flawed. We believe that medical ethics should always be set in the context of relationships and community. We believe that, if patient individualistic autonomy is to be the *sole* criterion for decision making, the patient–doctor relationship is reduced to that of client and technician. O’Neill<sup>11</sup> considers that “conceptions of individual autonomy cannot provide a sufficient and convincing starting point for bioethics, or even for medical ethics”. She concludes, “The supposed triumph of individual autonomy over other principles—is an unsustainable illusion”.

It might be argued that O’Neill’s critique of individualistic autonomy has already triumphed in medical ethics and that there is now no need for us to critique it further. John Harris provides a striking illustration that this is not so. In a recent issue of the *Journal of Medical Ethics* (in which O’Neill five pages earlier argues that “contemporary accounts of autonomy have lost touch with their Kantian origins, in which the links between autonomy and respect for persons are well argued”<sup>12</sup>) Harris claims that<sup>13</sup>: “Autonomy, the values expressed as the ability to choose and have the freedom to choose between competing conceptions of how to live and indeed of why we do so, is connected to individuality in that *it is only by the exercise of autonomy that our lives become in any sense our own*. By shaping our lives for ourselves we assert our own values and our individuality” (our italics).

Schneider<sup>1</sup> suggests that there are two current models of autonomy—optional and mandatory. Brock<sup>14</sup> defines the former as entitling but not requiring a patient to take an active role in decision making regarding treatment. In the latter model (characteristically adopted by Harris) “it is practically unwise and morally objectionable for the patient to forswear making medical decisions personally”.<sup>1</sup> Although this latter model seems to eliminate any residue of medical paternalism is it not in danger of replacing it with an equally (or possibly even more) unacceptable paternalism by bioethicists?

Building upon O’Neill, we recommend that a revision of the operational definition of patient autonomy is required for the twenty first century. We have been influenced by the following ideas: autonomy involving ethics as “the activity of—persons bound together in a common pursuit”<sup>10</sup>; patient autonomy as “the capacity to assess critically one’s basic desires and values, and to act on those that one endorses on reflection”<sup>15</sup>; and also “those actions and decisions that tend to promote the settled goals of the individual”.<sup>16</sup> In this model a patient is fully entitled, but not required, to take an active role in decision making regarding treatment. Adding these together, we suggest a principled version of patient autonomy that involves the provision of sufficient and understandable information and space for patients, who have the capacity to make a settled choice about medical interventions on themselves, to do so responsibly in a manner considerate to others. The extent to which they exercise their choices is an integral part of the process.

## TRUST AND AUTONOMY

In her Reith Lectures for 2002 entitled “A Question of Trust”, O’Neill<sup>4</sup> reminds us Confucius considered that the three things needed for government are weapons, food, and trust. If a ruler cannot hold on to all three they should give up weapons first and the food next. Trust should be guarded to the end because “without trust we cannot stand”. This applies to us all whether as individuals or part of a community, institution or profession because “we have to be able to rely on others acting as they say that they will, and because we need others to accept that we will act as we say we will”.<sup>10</sup> Trust and trustworthiness are two faces of the same coin. Without either there can be no valid currency. Trust is fundamental to a moral community<sup>17</sup> and arguably “the fundamental virtue at the heart of being a good doctor”.<sup>18</sup> Illingworth describes trust as the scarcest of medical resources.<sup>19</sup>

In her influential book *Autonomy and Trust in Bioethics*<sup>5</sup> (based on her Gifford Lectures in the University of Edinburgh in 2001) O’Neill maintains that “trust is not a response to certainty about others’ future actions”. Indeed, “trust is needed precisely when and because we lack certainty about others’ future actions”. Thus, there is an inevitable element of risk in placing one’s trust in someone or something that introduces a vulnerability to any relationship of trust. Thus “trust”, by definition, requires faith that in this context is defined as “committing to that of which we can never be sure”.<sup>20</sup> This does not mean that trust should be placed blindly. On the contrary, trust should only be placed in a person, object or organisation in the light of the best available evidence that he, she or it is trustworthy. Yancey reminds us, “a person who lives in faith must proceed on incomplete evidence, trusting in advance what will only make sense in reverse”.<sup>20</sup>

On what does trustworthiness depend? To be trusted one must, first, show that one is trustworthy. The most immediately obvious criterion is “track record” or demonstration of competence. His England team mates trusted that Jonny Wilkinson would drop that goal in the last seconds of the Rugby World Cup Final because of their past experience of his prowess and despite the uncertainty caused by him having already missed two such kicks in the match. A second important criterion is the means by which competence is gained and attested. For healthcare professionals to be deemed trustworthy the public must trust that the bodies responsible for their training and regulation are fit for those purposes and that the individual practitioner has satisfied their requirements and will continue to do so.

## PRINCIPLED AUTONOMY AND THE PATIENT–DOCTOR RELATIONSHIP

The patient–doctor relationship only works when each can trust the other. However, it can be argued that the imbalance of power usually heavily weighted in favour of the doctor means that he or she has the greater responsibility to be trustworthy. Schneider<sup>1</sup> has found autonomy to be striking by its absence in the concerns of people who are actually sick. He finds it interesting that autonomy should figure more in the thinking of people who are well and who are contemplating illness than it does in the thinking of those who are actually experiencing serious medical care. This might be part of a more or less conscious decision not to be involved in the making of decisions and that this is a way of giving meaning to what is happening in one’s own life, including one’s particular illness.<sup>21</sup> It is certainly interesting that the reaction of sick doctors can ironically be to prefer paternalism to personal autonomy.<sup>22</sup>

The patient–doctor relationship has traditionally been seen as covenantal rather than contractual. In the former there is a mutual, unspoken agreement between the parties that recognises the duties and obligations of each to the other.<sup>23</sup> Mutual trust is at the heart of this relationship and, unfortunately, trust has been eroded by a variety of high profile medical cases over recent years. As a result, it is now being suggested that the previous implicit compact among doctors, patients, and society has broken down. This is at a time when “managerial ethics” has become a powerful force in health care on both sides of the Atlantic backed by strong combination of government policy and commercial interest. As Jennings<sup>9</sup> points out, “Physician ethics tends to be patient-centred. ... Managerial ethics, by contrast, has to do with setting the stage for formations of collective action by a large number of individuals.” Thus, in this dominantly consequentialist model, it is not individuals (for example, doctors, nurses, dentists) but systems that ultimately determine the care to be provided for patients. At one level this move is understandable. The product, “health care”,

costs far too much of a nation's gross national product for its delivery to be left to those (for example, the aforementioned doctors, nurses, dentists) who are both deemed to be self-interested and acting as the advocates for their patients without understanding "the greater good". On the other hand the final common pathway for the delivery of that care is the healthcare professional and it is at that level that trust is gained and bestowed. The ballot box and the "free-market" are hardly adequate systems of accountability for Granny's incontinence or daughter Liz's premature baby! This approach is surely antithetical to a proper view of patient principled autonomy and Illingworth<sup>19</sup> considers that trust within the doctor-patient relationship has been impaired by such managed care. Although the government of the day in the UK and the managed care organisations in the USA have great influence in determining the type, range, and quality of care provided they carry no ultimate responsibility for it in relation to the sick person. It is still the individual doctor or nurse who carries the responsibility for the delivery of substandard care even if that truly lies in the system within which they are trying to work to the best of their abilities. The conflict between these models requires much greater consideration than is currently occurring.

In the traditional "covenant relationship" the central obligations of the doctor are competence, compassion, caring, and good communication. Recognition of their autonomy means that patients must be treated with respect, be properly informed, be listened to, give their consent voluntarily and without coercion, and have their confidentiality fully respected. In short, people should be treated as people and not simply as "patients". Atkins<sup>24</sup> argues for consideration of the subjective character of experience to understand fully a patient's situation. This is more than empathy in which one tries to consider what it would be like if one were in the situation in which the patient finds him or herself. In Atkins's view we should go even further and try to understand what it is like for *that person* to be himself or herself.<sup>24</sup> Does the patient have any reciprocal obligations? Draper and Sorell<sup>25</sup> have considered patients' responsibilities in medical ethics. They argue, "medical ethics is one-sided" because "it dwells on the ethical obligations of doctors to the exclusion of those of patients". They continue: "Traditionally medical ethics has asserted that, as autonomous agents, competent patients must be allowed to decide for themselves the course of their medical treatment." "It is for the doctor to communicate effectively all the relevant information, assess the patient's competence, persuade without coercing, and abide by whatever decision the patient makes. Little or nothing is said about what kinds of decisions a patient ought to make." "Indeed mainstream medical ethics implies that a competent patient's decision is good simply by virtue of having been made by the patient." They suggest that taking responsibility for what is chosen is intrinsic to the exercise of autonomy. In practice this may be manifested in two very different ways. In the first, the very act of taking responsibility for an autonomous decision about one's health may make it more effective. For example, a freely reached decision to stop smoking is more likely to succeed than any external attempt to ban it. On the other hand, if one freely chooses and consents to an option with a specific risk of an adverse or unwanted outcome that has been fully explained, one can have no complaint if that adverse outcome occurs despite the procedure being performed competently. Thus, a woman with multiple fibroids who requests myomectomy and who is informed of a small risk that hysterectomy may be required and consents to the procedure on that basis, has no cause for complaint if it does actually occur even if the myomectomy were performed competently. Another very important issue falls within this second category, namely what is the

responsibility of the individual for the effects of lifestyle on their health? This debate certainly needs more serious consideration than it is currently given.

Public health medicine poses other interesting dilemmas in the context of personal autonomy. Those who, for example, successfully oppose mass fluoridisation of water may be willing to trade the consequences for their own dental health against their perception of even a slight and, possibly, theoretical overall risk. How is this to be reconciled with the much greater good for the dental health of the whole population that would derive from mass fluoridisation of water? In considering public health versus individual benefit, Brock and Wartman<sup>26</sup> suggest that patients do not have an unqualified right to make even rational individual choices that risk serious harm to others.

## CHOICE OF TREATMENT

Properly understood in ethical terms choice/consent is typically a process rather than a single act. The term "informed choice" is often to be preferred over "informed consent". Choice implies offering options from which patients can indicate their preference (including none!). Properly informed choice and consent are very important in medical ethics. The best practice that expresses a proper patient-doctor relationship in which each fully respects the true autonomy of the other has several components. There is, first, an unspoken covenant of trust between the doctor and patient that the latter's wishes expressed in the consent process will be honoured. It also typically involves a full and comprehensible explanation by the doctor of the problem(s) requiring intervention followed by an authoritative statement of the benefits and risks of the various options (including doing nothing). To reach a freely arrived at decision about their preferred choice (including no intervention and a wish *not* to make a decision), patients must understand the information provided and be given time to consider the options. (The appropriate length of time will vary depending on, for example, the urgency of the situation and a patient's state of mind, need for reflection and, perhaps discussion with family members.) This culminates in the gaining of valid consent to any procedure based intervention.

Unfortunately the very complexity of some areas of medical practice makes it difficult to make sure that patients have given their consent on the basis of properly informed choice. For example, some of the new developments in fertility treatment may require a basic knowledge of human biology beyond some patients. In addition their illness may render the patient even less able to consider these complexities. These, however, increase rather than lessen the doctor's responsibility to impart the information in a way patients are best able to understand in the context of their condition and status. Brock and Wartman<sup>26</sup> advocate shared decision making that "respects the patient's right of self-determination but does not require that the patient's preferences be simply accepted when they seem irrational". They note, however, that distinguishing irrational preferences from those that simply express different attitudes, values and beliefs can be "difficult in theory and practice".<sup>26</sup> To this dialogue doctors bring their medical training, knowledge, and expertise. Patients bring their narrative and knowledge of their own subjective aims and values. Selection of the best treatment for each patient requires the contribution of both parties.<sup>26</sup>

Baylis and Sherwin<sup>27</sup> suggest reasons why some women may reject the advice from obstetricians about their care during pregnancy. It may, for example, be due to the attitude of the doctors involved; or be because the advice runs contrary to the woman's values. An example of the latter would be if a woman has undergone fertility treatment and is now carrying three or more fetuses. She may be advised to undergo selective

termination but, being adamantly opposed to abortion, she refuses. Among other suggested reasons is that there may be epistemological conflict leading to fundamental disagreement about the grounds on which medical knowledge is based. This can arise as a result of the intrinsic lack of certainty of medical knowledge, very different advice being given on the same clinical issue by different doctors, past tragic failures (for example, use of thalidomide in pregnancy) or past personal or family experience. She may distrust doctors, fail to understand the issues, or be afraid. There may be just too much advice “and it is simply not practical for anyone to follow it all”<sup>27</sup> or it may result from other concerns and constraints on her life (for example, demands of work, children, or social circumstances such as being a single parent, having an uncaring or abusive partner, and poverty). Of course, the reasons for rejecting the advice may not be fully understood even by the woman herself.

Brock and Wartman<sup>26</sup> remind us that even truly irrational choices are not sufficient to establish a patient’s incompetence and to justify overriding them. A competent patient has the legal right to refuse medical treatment or intervention and doctors should not then intervene medically, however justified that intervention might be in medical terms. Among the areas in which this has at present been tested are performing a caesarean section against the wishes of the woman involved, sterilising a woman without her consent during an operation for other purposes, and removing healthy ovaries at hysterectomy without specific consent.

## REQUESTS FOR TREATMENT

A potential clash occurs between the (individualistic) autonomy of patient and doctor in those situations where a patient requests, or even demands, a particular form of treatment and the doctor considers it to be unjustified (or may currently be illegal, for example, euthanasia). This can, for example, be because:

- in his or her informed opinion the risk of the procedure outweighs the potential benefits
- it is medically inappropriate for that patient
- it would consume a scarce resource needed by other patients whose needs have a higher priority.

A patient does not have a right to any specific intervention if that would be detrimental to the rights of others. Among the possible examples giving rise to conflict are a request for the removal of a healthy limb because an otherwise competent person considers it to be diseased, or the more mainstream requests for elective caesarean section in the absence of any obstetric indication, and some novel forms of fertility treatment. It can also apply when the patient is requesting an intervention to which the doctor has a moral objection—for example, termination of pregnancy or female genital mutilation. In the former, the doctor is considered to have a duty to refer the woman to another practitioner. This would not apply to the latter even if it were not illegal in the UK. The difference is justified in law but the ethics are less straightforward. Of the above criteria, the first two are more easily ethically justified than the third. In the first two, the doctor is acting on his or her informed view of the patient’s best interests. The third is much more difficult to justify and enters the problematic area of rationing and priorities that is outside the scope of this paper.

## CONCLUSION

We believe that the individualistic version of autonomous choice is fundamentally flawed and that medical ethics should always be set in the context of relationships and community.<sup>3</sup> We suggest a principled version of patient

autonomy that involves the provision of sufficient and understandable information and space for patients, who has the capacity to make a settled choice about medical interventions on themselves, to do so responsibly in a manner considerate to others. We consider that this model best fits the optimal patient–doctor relationship in which there is a mutual, unspoken agreement between the parties that recognises the duties and obligations each to the other.<sup>23</sup> Bilateral trust is at the heart of this relationship.

Exercise by doctors of their clinical judgement is frequently attacked as “paternalism”. In some instances this can be so, but it may also be the doctor fulfilling his or her duty to the patient by exercising his or her own autonomy and, as such, may be entirely justified. Indeed, there will be some occasions in which acquiescence to a requested intervention against one’s clinical or ethical judgement will be abrogation of one’s duty as a doctor.

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