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The Linacre Quarterly

Volume 53 | Number 2 Article 8

May 1986

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Recommended Citation
Johnson, Paul R. (1986) "Patient Autonomy in Decision Making: Recent Trends in Medical Ethics," *The Linacre Quarterly*: Vol. 53 : No. 2 , Article 8.
Available at: http://epublications.marquette.edu/lnq/vol53/iss2/8

Patient Autonomy in Decision Making: Recent Trends in Medical Ethics

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Introduction

Although the tension between the principles of paternalism and patient autonomy has a long history in medicine and medical ethics, the recent past has seen an increasing change in emphasis in the direction of the rights of patient self-determination. This should not be surprising, given the general socio-cultural and philosophical mood in this century which has placed special priority on human rights, individualism, and the questioning of authority. Haug and Lavin see the expression of this movement in the field of medicine as issuing in "medical consumerism, self-help, the patients' rights movement, and the re-evaluation of professional authority . . ."[1] In response to this, closer scrutiny is being given to the concept of autonomy. This has resulted in (1) refinement in the definition of autonomy, (2) a greater recognition of the phenomenon of limited autonomy, and (3) the emergence of autonomy not only as a principle to be upheld, but also a goal to be achieved.

In their survey of its historical development, Beauchamp and McCollough cite both acient and modern sources for the principles of paternalism and autonomy in medical ethics.[2] It seems clear, however, that the former, which they refer to as the Beneficence Model, was earlier the more dominant principle. Both Beauchamp and McCollough and Robert

Veatch describe the Hippocratic Oath and the tradition which followed it as centered on the underlying value of beneficence. "Those who have stood in that tradition are committed to producing good for their patient and to protecting that patient from harm."[3] The Hippocratic tradition, with its emphasis on beneficence and consequent tendency toward paternalism, has been the central theme of historical medicine and medical ethics. Even modern medical codes of ethics, such as those drawn up by the American and World Medical Associations, have reflected this tradition. For example, it was not until the 1957 and 1980 formulations of the code of the AMA that there was a noted strengthening of attention to patients' rights perspectives.

> Only in these very recent versions . . . did the Hippocratic commitment to benefit exclusively the patient, according to the physician's judgment, begin to give way to other ethical commitments — those that take into account the interests of the rest of society; . . . and those that take into account the judgment of patients and others beyond the physician.[4]

On the other hand, attention to the principle of patient autonomy, while always incipient in commitments to respect for individuals, came to the fore in more recent times. The philosophical groundwork for the modern emphasis on autonomy is laid in the writings of Kant and Mill.[5] In Kant, attention is given to the importance of the autonomous will as freely determining its own values — self-determination according to universalizable moral principles accepted by the individual. Mill, on the other hand, gives his attention to freedom of action and thought as leading to the full development of the individual and, thereby, of society. Kant focuses on the *internal* development of will, while Mill focuses more on *external* lack of constraint. But in either case, respect for the autonomous decisions of others is a central value, both because of the inherent worth of the other (Kant) and because social liberty will be most conducive to the full flowering of the individual (Mill).

Thus, the principle of autonomy has come to be defined as referring to self-rule, self-regulation, self-determination. "It asserts a right of non-interference and, correlatively, an obligation not to constrain autonomous actions . . ."[6] The principle of autonomy, like that of beneficence-paternalism, has been readily adapted to the setting of medical ethics and recently has been more and more expressed in legal decisions. A clear example of this is the following statement from Natanson v. Kline (Kansas, 1980): "A doctor might well believe that an operation or form of treatment is desirable or necessary but the law does not permit him to substitute his own judgment for that of the patient by any form of artifice or deception."[7] Hence, it would appear that autonomy is beginning to take precedence over paternalism in contemporary medical ethics. And, in many circumstances, this is true. But its prominence has also brought increased attention to the concept of autonomy itself. And this attention is producing a modified and more sophisticated use of the principle.

I

This increased sophistication is showing itself first in a refinement of the definition of autonomy. This is being approached from two directions — a critique of the traditional definition and proposals for a deeper and more complex analysis of the concept. In both approaches, the influence of the clinical experience of medicine as well as sociological and psychological disciplines is apparent.

The traditional understanding of autonomy has tended to focus on the principle in the abstract, i.e., the right of self-determination which is a corollary of the fundamental worth and dignity of the individual human person. That the freedom of thought and action which which is presupposed by this principle does not readily appear in the world-as-experienced, soon became evident under the examination of the social and psychological sciences. Sociology proposed various levels of "soft" or "hard" determination of human behavior by social forces. Behaviorist psychology has agreed even to the point of questioning the validity of looking for internal determinants of human behavior. On the other hand, the Freudian tradition of psychology looks to intrapsychic forces as giving often unrecognized direction to only apparently conscious activity. Willard Gaylin concludes, "Putting it in a different way, increasing knowledge of the causes of human behavior reduces the role of a supposed free agent to whom we credit behavior."[8] The limits on autonomous actions imposed by factors such as age, mental capacity, etc., were recognized in early philosophic analyses of the concept, but are being given greater weight in recent discussion. Thus there have been serious questions raised about the degree of true autonomy of persons assumed by the abstract definition of the principle.

It is not only the pragmatic question of establishing relatively free self-determination which has been part of the critique of the traditional idea of autonomy. It has been found limited on a more philosophic level of analysis as well. William May, for example, has questioned the contractual model of relations between health care providers and patients, which seems to be implied by primary emphasis on autonomy. In its place he proposed the ideal of "covenant."[9] This recognizes an obligation of the physician which goes beyond the specific duties imposed by individual acts of agreement. Such obligation calls for a more activist role for physicians in pursuing patient well-being. At the same time, covenantal bonds may call for patients to recognize certain areas of legitimate expertise and responsibility among health care providers. While May does not seek to restore the paternalistic model of medicine to prominence, an opening for a more restricted role for autonomy is present in his model.

Daniel Callahan also finds the traditional statement of autonomy to be weak. On philosophical as well as practical grounds, he sees autonomy as a moral good which has been pushed into becoming a "moral obsession." This, in turn, has brought about a "minimalist ethic" which does not do

justice to the full human moral experience."[10] Callahan summarizes this autonomy-based minimalist ethic in the proposition that "one may morally act in any way one chooses so far as one does not do harm to others."[11] Such an ethic is faulty, he argues, on several grounds. (1) We are led to a society characterized by moral isolation rather than moral community. (2) The existential intermingling of private and public spheres is overlooked by a sharp distinction between them. (3) Moral dialogue over issues of social concern — e.g., the common good, justice, etc., — is reduced to bartering individual choices. (4) The sense of moral obligation is reduced in the direction of only those which are individually contracted. (5) The call to respect the autonomy of others can too easily lead to the overriding of one's conscience. Thus, Callahan, like May, sees the general concept of autonomy open to critique not only in terms of psycho-social restrictions but in terms of philosophical shortcomings as well.

The second part of the refinement of the concept of autonomy, concomitant with the critique just described, has appeared in proposals for a more sophisticated definition or understanding of the experience of autonomy. Of particular note here are the analyses of Gerald Dvorkin and Bruce Miller. Dvorkin has suggested that autonomy be defined as "authenticity under the conditions of procedural independence."[12] Here he describes the two components of autonomy as independence and authenticity. The former is common to traditional definitions of autonomy. Dvorkin suggests we need to investigate actions which may prompt a person to do something without infringing on his freedom. His discussion of modes of behavior control suggests guidelines for such non-coercive activity. Among these are procedures which (1) support the ability to think rationally, (2) rely on knowledge rather than deception, (3) maintain the continuity of an individual's personal identity, and (4) depend on the active participation of the person.

Dvorkin's other criteria, authenticity, is less fully explored than that of independence. However, it is clear that he is referring to the "ownership" of a person's motivations by that person. He is concerned that a person's choices, whatever prior conditioning they may have in family, society, etc., be his or her own. Thus, "it is the attitude a person takes towards the influences motivating him which determines whether or not they are to be considered 'his'. Does he identify with them, assimilate them to himself . . .?"[13] In this manner, Dvorkin is beginning to deepen the concept of autonomy not only by exploring the ideal of independent action but by raising the question of the relation of action to the "true self".

Bruce Miller carries this type of analysis further. He distinguishes four senses of autonomy — autonomy as free action, as authenticity, as effective deliberation, and as moral reflection.[14] Like Dvorkin, Miller stresses independence in his analysis of autonomy as free action. Action that is free he describes as voluntary, that is, "not the result of coercion, duress, or undue influence", and intentional, that is, the conscious goal of the person. Miller adds clarity to Dvorkin's idea of authenticity as an

aspect of autonomy. Authenticity, he argues, "means that an action is consistent with the person's attitudes, values, dispositions, and life plans. Roughly, the person is acting in character."[15]

Autonomy as effective deliberation focuses on the process of decision making. This calls for knowledge of decision alternatives and the consequences of those alternatives, and a process of weighing or evaluating those alternatives. Recognizing that the health care provider may be tempted to equate effective deliberation with the patient agreeing with the professional medical advice, Miller proposes safeguards which he thinks may hold such a possibility in check. He suggests that the patient's knowledge should not be viewed as having to be equivalent to the physician's, and that the rationality of the weighing or evaluation should be viewed in the context of consistency with the patient's other values (cf. authenticity) rather than the doctor's values.[16] Miller pushes the concept of deliberation even further in the direction of self-knowledge as assumed in the idea of autonomy as moral reflection. This sense of autonomy is seen as the "deepest" and "most demanding" because it involves "reflection on one's complete set of values, attitudes and life plans. It requires rigorous self-analysis, awareness of alternative sets of values, commitment to a method for assessing them, and an ability to put them into place."[17] While Miller seems to view this sense of autonomy as separate from the others, it might equally be seen as a deeper form of authenticity, i.e., a bringing to full consciousness and reflection of the values central to one's self.

II

Thus, we have seen a clarification and an increase in sophistication of the understanding of autonomy. Having been tested against the critique of socio-psychological analysis and philosophical questioning, autonomy has grown to be defined more carefully in terms of levels of experience from uncoerced thought and action to the correlation of action with the core identity values of the reflective self. Accompanying this refining of the definition of autonomy is an increased recognition of limited autonomy and an appreciation of its significance for the obligation to respect patient self-determination. It has become standard to recognize certain natural limitations to those types of persons who can be considered autonomous. Those who lack full mental ability, e.g., children, the senile, the greatly retarded, the comatose, etc., are normally seen as non-autonomous, as are the mentally ill, those temporarily irrational due to drug-dependence, and those who are coerced. In situations such as these, there is a general acceptance of the moral legitimacy of beneficent proxy consent. Such consent is, as we shall see below, in the broadest sense of the word, paternalism — a choice made for someone else based on benefit to that person.

The concept of limited autonomy, however, has been given even further exploration. On the more theoretical level, Bruce Miller returns to his fourfold analysis of autonomy to suggest that autonomy can be limited in

one of several ways.[18] (1) The patient may not be autonomous if action or choice is not free, that is, if the person is being coerced by factors external, or perhaps even internal, to himself. (2) The autonomy of a person may be questioned if the patient is acting "out of character", i.e., not authentically in keeping with his known pattern of values, dispositions, etc. (3) If the patient does not have a reasonable knowledge of alternative choices and their consequences, or seems to be evaluating them on criteria out of keeping with previously established values, he may not be acting autonomously. (4) Miller has some difficulty in applying the fourth sense of autonomy — moral reflection — to determining that a person may have limited autonomy. But since there seems to be a natural linkage between what Miller calls moral reflection and the more general phenomenon of what he calls authenticity, we may be able to treat them as one phenomenon. Thus, in order to determine the non-autonomy, and thereby candidacy for paternalistic treatment, of a patient, Miller would have us assess the natural or situationally induced limitations in these forms of autonomy.

In an even more specific way, the effect of illness on autonomy can be examined. Mark Komrad, noting that "autonomy is neither permanent nor immutable, but . . . a dynamic state liable to perturbation" and that physical distress can interfere with both reasoning and freedom of action, suggests that "all illness represents a state of diminished autonomy."[19] Following Dvorkin's categories, Eric Cassell notes that illness may affect both authenticity and independence.[20] Physical changes may cause a patient to lose, at least temporarily, a sense of continuing personal identity. And pain and suffering may impair clear thinking, especially in light of the limited medical knowledge a patient may have access to or understand. Thus both authenticity and independence of action may be diminished. Younger and Jackson, medical faculty members at Case Western Reserve University, spell out further ways in which illness and the resulting clinical setting of a patient can cause action that is not truly autonomous.[21] Patients' decisions can be based on temporary reactive depression, on fear arising from misperception or misinformation concerning one's status. They may be an expression of only one side of what are actually ambivalent feelings, or of a symbolic attempt to gain control of their situation through arbitrary choice of actions contrary to the decisions of those around them, whether family or medical staff.

Although the judgment that a given patient is non-autonomous in any of the senses cited above is not always an easy task and may be open to abuse by an overzealous or undersensitive health care provider, there seems little doubt that limited autonomy is a real phenomenon and, as such, must be considered in any complete moral analysis of issues surrounding patient self-determination. What preliminary conclusions might be drawn from decisions about action in such contexts? Is this a situation in which paternalism may be called on to be the active moral principle? The answer seems to be a modified "yes" on two counts.

Paternalism, as traditionally defined, is set in strong contrast to respect for autonomy. Modifying Dvorkin's widely cited definition, Jane Zembaty defines paternalism as "interference with a person's autonomy justified by reasons referring exclusively to the welfare, good, happiness, needs, interests or values of the person being constrained."[22] To the degree that paternalism is understood as action contrary to another person's autonomy, one might argue that decisions for patients of limited autonomy are not actually paternalistic, i.e., we cannot violate the autonomy of one who is not autonomous or is so only to a limited degree. "Sound decision making need not run counter to patient autonomy; it can involve the judgment that the patient's . . . (decision) . . . is not autonomous in the appropriate sense."[23] The action is, then, simply one of proxy consent, in which the primary moral principle is beneficence.[24]

Or can we begin our definition of paternalism closer to the concept of beneficent proxy consent and see it as justified when (1) harms prevented or benefits provided to the person outweigh interference with independence, and (2) the person's condition is one of seriously limited autonomy, and (3) such interference would be universalizable to similar circumstances.[25] Those who follow this approach make significant use of Joel Feinberg's distinction between strong and weak paternalism. The former, according to Beauchamp and Childress, involves actions "to protect a person by limiting his or her liberty even when that person's choices are informed and voluntary," whereas weak paternalism occurs where the person's actions are non-voluntary or insubstantially informed.[26] Such weak paternalism may also take two forms. It may lead to actual proxy consent, there being no or insufficient autonomy to be considered violated. Or it may involve temporary intervention or refusal to comply with the patient's wishes until it can be established that his or her choices are, in fact, voluntary, that is, weak paternalism may be invoked until the person's autonomy of action can be verified. This seems clearly one of the strong motivations of those proposing delay in immediate response to certain patient wishes.[27]

Thus, viewed in the light of the recognition of the phenomenon of limited autonomy, a form of paternalism may occur which is not at its core a true violation of respect for autonomy. On the one hand, autonomy is not violated if autonomy is not actually present. On the other, autonomy is actually upheld since the intervention is limited to the time necessary to ascertain autonomy. If autonomy is found to be present and being acted on, it is then recognized and the person's choice of action honored.

III

There is one further way in which the use of the idea of autonomy in recent medical ethics is being revised. The discussion above has basically seen the concept of autonomy in static terms, as a principle to be honored or rejected in favor of another principle. Even paternalistic intervention viewed autonomy either as a principle that did not apply (i.e., where the

patient was not autonomous) or one that could be applied as soon as the patient's autonomous condition was confirmed. But an important variant of this outlook is also emerging — one which sees autonomy not just as a moral principle, but also as a therapeutic goal.

Recognizing the phenomenon of limited autonomy, Eric Cassell sees it not simply as a status to be acknowledged, but as a debility to be overcome, a weakness to be reversed, a deficient ability which needs strengthening. As previously noted, he sees illness as imparing autonomy. But, for Cassell, the goal of medicine is not just the treatment of disease entities. He states, "I believe the function of medicine is to preserve autonomy . . . It is obvious that the best way to preserve autonomy is to cure the patient of the disease that impairs autonomy and return him to his normal life."[28] Paternalism, particularly the weak paternalism described above, thus honors autonomy by seeking to bring it about. The goal of physician paternalism is not simply to be the imposition of a preferred course of treatment, but the maintaining or restoring of patient autonomy so that it can be exercised and honored in future treatment choices. Mark Komrad makes this point forcefully.

> The restitution of diminished autonomy is the only rationalization of medical paternalism that does not profane autonomy. The admonition that a physician should 'respect the patient's autonomy' does not explicity acknowledge that a patient presents a condition of incomplete autonomy. Rather, one might more appropriately ask instead that the doctor respect the patient's *potential for autonomy*. The maximization of autonomy within the bounds of the patient's potential seems to me a legitimate goal of the therapeutic encounter . . . The *raison d'etre* of limited paternalism is to preserve an individual's freedom as much as possible in the hope of eventually broadening it.

Jane Zembaty takes a similar position and justifies it against presumed utilitarian and deontological defenders of a stricter interpretation of the principle of respect for autonomy. Against the utilitarian, she argues, "As long as the high value placed on individual autonomy serves as the ground for the utilitarian rejection of medical paternalism, it would seem incoherent to claim that paternalistic actions *intended to preserve that autonomy* are ethically unjustifiable;" and against the deontologist, she suggests, "If the patient's humanity or personhood consists in 'choosng and being able to judge his own ends,' then paternalistic actions whose intent is to preserve the individual's ability to choose or judge his own ends would again seem to be justified."[30]

The importance of this position, i.e., autonomy as a therapeutic goal, is twofold. First, it recognizes the dynamic nature of human phenomena, autonomy in particular, and draws it away from abstraction and more closely into the world as lived by real patients and real health care providers. And second, it may help inhibit the all too easy slip from weak to strong paternalism. Keeping autonomy as a conscious goal of medical treatment maintains a higher priority on long term and ultimate patient self-determination.

Conclusion

Although paternalism, particularly strong paternalism, no longer plays the dominant role in medical ethics today, it is also clear that the principle of respect for autonomy has itself undergone some modification. Robert Veatch, one of patient autonomy's strongest proponents in contemporary medical ethics, may still argue that "the case is overwhelming that autonomy takes moral precedence over paternalism. Respecting the patient's autonomy always takes precedence over benefitting the patient against the patient's autonomous will."[31] But most of even those who agree with him in general have begun to refine what they would mean by such a statement.

The abstract definition of autonomy has been tempered by the recognition of its several levels as an existential human phenomenon. The acknowledgement of the clinical reality of limited autonomy has opened the door for a modest accommodation with paternalism, at least with weak paternalism. This type of paternalism is seen to maintain a certain deference to the principle of respect for autonomy. This deference is especially seen in the emergence of autonomy as a therapeutic goal for medicine. It remains on the agenda for future medical ethics to pursue specification and implications of these refinements.

NOTES

1. Cited in Mark Komrad, "A Defence of Medical Paternalism: Maximising Patients' Autonomy," *Journal of Medical Ethics* 9:1 (1983) p. 38.

2. Beauchamp, Tom, and McCollough, Laurence, *Medical Ethics: The Moral Responsibility of Physicians* (Prentice Hall, 1984), pp. 27-35, 42-46.

3. Veatch, Robert, *A Theory of Medical Ethics* (Basic Books, 1981), p. 22.

4. *Ibid*, p. 25.

5. Beauchamp, Tom, and Childress, James, *Principles of Biomedical Ethics*, 2nd ed. (Oxford, 1983), pp. 60-62.

6. *Ibid*, p. 62.

7. Cited in Beauchamp and McCollough, p. 43.

8. Gaylin, Willard, "In Defence of the Dignity of Being Human," *Hastings Center Report* 14:4 (August, 1984), p. 19.

9. May, William F., *The Physician's Covenant: Images of the Healer in Medical Ethics* (Westminister, 1983).

10. Callahan, Daniel, "Minimalist Ethics," *Hastings Center Report* 11:5 (October, 1981), pp. 19-25; and "Autonomy: A Moral Good, Not a Moral Obsession," *Hastings Center Report* 14:5 (October, 1984), pp. 40-42.

11. Callahan, "Minimalist Ethics," p. 20.

12. Dvorkin, Gerald, "Autonomy and Behavior Control," *Hasting Center Report* 6:1 (February, 1976), p. 26.

13. Dvorkin, p. 25.

14. Miller, Bruce, "Autonomy and the Refusal of Lifesaving Treatment," *Hasting Center Report* 11:4 (August, 1981), pp. 22-28; and "Patient Autonomy in Intensive Care," *Progress in Clinical and Biological Research* 139 (1983), pp. 111-124.

15. Miller, "Autonomy," p. 25.

16. Miller, "Patient Autonomy," p. 117.
17. Miller, "Autonomy," p. 25.
18. Miller, "Autonomy," and "Patient Autonomy."
19. Komrad, p. 41.
20. Cassell, Eric, "The Function of Medicine," *Hastings Center Report* 7:6 (December, 1977), p. 17.
21. Younger, Stuart, and Jackson, David, "Family Wishes and Patient Autonomy: Commentary," *Hastings Center Report* 10:5 (October, 1980), pp. 21-22.
22. Zembaty, Jane, "A Limited Defense of Paternalism in Medicine," *Biomedical Ethics*, edited by Thomas Mappes and Jane Zembaty (McGraw-Hill, 1981), p. 57.
23. Miller, "Autonomy," p. 27. See also Beauchamp and Childress, p. 175.
24. The question of who shall serve as proxy will not be pursued here. I presume the general priority of family or patient-appointed proxy. On the matter of the centrality of beneficence in proxy consent, see Paul R. Johnson, "Proxy Consent in Life and Death Decisions," *Contemporary Philosophy* VIII:4 (Fall, 1980), pp. 9-10.
25. Beauchamp and Childress, p. 172.
26. Beauchamp and Childress, p. 175. See also Zembaty, note 4, p. 61.
27. Cassell, pp. 16-17; Younger and Jackson, pp. 21-22; Mark Ruddick, "Family Wishes and Patient Autonomy: Commentary," *Hastings Center Report* 10:5 (October, 1980), p.22; Mark Seigler, "Critical Illness: The Limits of Autonomy," *Hastings Center Report* 7:5 (October 1977), p. 13. For an elaborate proposal of a method of determining competence to consent, a concern central to the more general concept of autonomy, see Elias Baumgarten, "Patient Autonomy and the Refusal of Psychotropic Medications," *Progress in Clinical and Biological Research* 139 (1983), pp. 19-28.
28. Cassett, p. 18.
29. Komrad, p. 42. In a related approach, Onara O'Neill argues that even the limited autonomy a person has can be honored by medicine's commitment to recognizing and enhance it. To respect others' autonomy requires that we make consent *possible* for them, taking into account whatever partial autonomy they may have." Onara O'Neill, "Paternalism and Partial Autonomy" *Journal of Medical Ethics* 10:4 (December, 1984), p. 175.
30. Zembaty, p. 59.
31. Veatch, Robert, "Autonomy's Temporary Triumph," *Hastings Center Report* 14:5 (October, 1984), p. 38.