

CAN THE CONDITION OF BEING TERMINALLY ILL COERCE PERSONS INTO ENROLLING IN RESEARCH?

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A close examination of the research ethics literature reveals that there are a number of ethicists who hold that experimenting on terminally ill persons poses a number of moral challenges, the most prominent being that terminally ill persons often fail to provide legitimate consent because they are "coerced" into enrolling in research by their disease.¹ However, many have challenged such accounts, arguing that situations cannot be coercive.² These accounts, however, have been inadequate as they have merely appealed to definition and tradition to claim that only persons can coerce or prevent persons from acting voluntarily.³ In this paper, I will defend the notion that terminally ill persons are not in coercive situations by showing that:

- (a) Coercion *always* prevents persons from meeting the voluntariness criterion that is necessary for giving legitimate consent.
- (b) Terminally ill persons who are asked to participate in research are not in situations which prevent them from meeting the voluntariness criterion.
- (c) Therefore, terminally ill persons do not find themselves in coercive situations.

To make this argument it is important to first provide an in-depth analysis of what it means to act freely in general as it is difficult to understand how coercive actions prevent the voluntariness criterion from being met without first understanding the nature of this criterion. I will focus my discussion on what I regard as being the most well-known theories of free action given the tremendous amount of literature that has been written about this topic.

Perhaps the most commonly held theory of free action holds that to act freely is to have the ability to act otherwise.⁴ This theory can be specified as follows:

X freely performs A only if X could at the same time not perform A.

While many persons may initially find this theory of free action to be intuitively plausible, as many philosophers have noted, if causal determinism is true, then according to this definition it cannot be the case that we are able to act freely as it is not possible for us to be act otherwise at any given time.⁵ However, putting the determinism issue aside, a more pressing problem with this theory is that it cannot account for all the cases in which a person appears to act involuntarily. For example:

Y threatens X to do A. While it is very difficult for X to resist Y's threat, it is still possible for her not to comply.

For many of us, if X complied with such a threat, then it seems counterintuitive to claim that she acted voluntarily. However, X acts freely according to this theory of free action.

Similarly, this account seems to suggest that persuasion can prevent persons from acting freely. For example:

If X performs A because she has been persuaded to do so by an effective rational argument and X is unable to NOT perform A as a result of this argument

According to this account, X does not act freely in this situation. Such a conclusion at its face appears implausible.

However, there are a number of theories of free action that do not depend on alternative possibilities. Among such theories, Harry Frankfurt's is perhaps the most well known.⁶ According to Frankfurt a free action involves not only being in a position to do what one wants but *wanting what one wants*. One wants what one wants when one reflectively controls and identifies with one's lower order desires through higher level desires or preferences. One's lower order desires are those desires which have as their object the actions of the agent. He calls any desire which has as its object another desire, a higher order desire.

A number of philosophers, however, have argued that there is no reason to assume that an action is free merely because one desires to have the desire to perform that action.⁷ For example, as Beauchamp and Childress point out "potent first order desires from a condition such as alcohol addiction are antithetical to autonomy and can cause second order desires."⁸ Therefore, these theories must also show that these second order desires themselves are autonomous if they are to have any plausibility.

Finally, it is important to consider an account of free action that appears frequently in the bioethics literature. A number of notable ethicists such Baruch Brody and Beauchamp and Childress have tried to define what it is for an action to be free negatively. For example, Baruch Brody writes:

Voluntariness involves individuals making decisions that are theirs and free of excessive inappropriate external influences.⁹

The above definition allows for situations to prevent individuals from acting voluntarily. However, this theory is quite vague as it only seems to state that an action is free so long as certain undue influences are not present. In order to ultimately assess its plausibility, it is important to identify a set of criteria for determining which influences prevent persons from acting voluntarily.

One way to accomplish this task is to consider those paradigm examples of influences, which prevent the voluntariness criterion from being met. If we look at the ethics literature, we see that acts of coercion meet this description. While I will present a much more detailed description of these acts later in this paper, for now I will briefly claim that such acts are thought to prevent a person from acting voluntarily because they are forms of influence which:

- (1) are irresistible or difficult to resist.
- (2) result in the person being influenced performing some action that she does not welcome because it brings her below a moral baseline. (It should be noted I employ the definition that Alan Wertheimer invokes which claims that to be brought below a moral baseline is to fail to have one's moral rights respected.)

and

- (3) take place in circumstances in which one "can reasonably reject a principle that took choices made under those conditions to create binding or enforceable obligations."¹⁰

This theory has many virtues. It escapes any problems that arise from assuming that free action requires the ability to do otherwise because (1) it can accommodate cases in which a person appears to be acting involuntarily despite having the ability to do

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otherwise as well as cases in which a person appears to be acting voluntarily despite not having the ability to do otherwise, and (2) it does not assume the falsity of causal determinism. Moreover, unlike the autonomy as free action theories, it is not necessary to provide a satisfactory account of what makes the higher order values autonomous in order to be feasible. Finally, as noted by Beauchamp and Childress, such an account does not present “an ideal beyond the reach of normal agents and choosers.”¹¹

Having clarified what it means to voluntarily consent to participate in research, I will now define what it means to engage in acts of coercion and show how such acts result in a defect in voluntariness before examining whether there are a number of situations which resemble these forms of influence.

One of the ways that one person can coerce another is through the use of coercive threats. In this paper, I will appeal to the definition that Alan Wertheimer provides. According to Wertheimer, the following set of descriptions capture what occurs when one person successfully coerces another using a threat¹²:

- (1) A wants B to perform X, so A threatens B.
- (2) A’s threat contains the demand to do X.
- (3) A has altered the situation, so that B views the option of complying with the demand (doing X) and the option of paying the cost of noncompliance as the only available alternatives.
- (4) Both complying with the demand (doing X) and paying the cost of noncompliance make the recipient worse off by bringing her below some relevant baseline.
- (5) The cost of not complying with the demand is significantly worse than the cost of complying with the demand.
- (6) B is strongly compelled to choose to do X in light of A’s threat.

It should be noted that Wertheimer does not explicitly mention criterion 5; nevertheless such a criterion seems to be necessary if we want to account for why A is compelled to do X.

It is important to clarify what is meant by the term “relevant baseline.” As Wertheimer observes, A can make B worse off in respect to four baselines¹³:

- (1) A may propose to make B worse off than B’s status quo or pre-proposal baseline.
- (2) A may propose to make B worse off than what B can “statistically” expect in the normal course of events.
- (3) A may propose to make B worse off relative to what B subjectively experiences as her baseline.
- (4) A may propose to make B worse off relative to where B has a moral right to be.

As I stated in the previous section where I discussed what it means for an action to be voluntary, coercive acts are thought to prevent a person from acting voluntarily in part because they are forms of influence which result in the person being influenced performing some action that she does not welcome because it brings her below a moral baseline. It is clear then that I am assuming that in the case of coercive acts the only relevant baseline is the fourth baseline.

The reason I hold this view is because it is possible to consider instances in which complying with A's demand and not complying with A's demand both bring B below baselines (1)-(3) but where it is apparent that B is not being subject to a coercive threat. It strikes me that there is a close relationship between coercive actions and moral responsibility. As I noted in the previous section on free action, if A's proposal is a coercive threat then B is not required to uphold the terms of any agreements which arise as a result of being coerced. Bearing this in mind, consider the following case:

B steals A's car. Several days later A sees B driving her car. A manages to get B to pull over. A threatens to call the cops on B unless B relinquishes A's car back to her. B complies with A's request.

In this instance both complying with A's request and not complying with A's request can bring B below baselines (1)-(3). If B rejects A's proposal, B will be worse off than she was prior to encountering A or that she could expect in the normal course of events, absent A's proposal. B may also feel that both options bring her below what she subjectively experiences as her baseline. Nevertheless, it seems strange to think that B has been coerced in giving back A's car as this would suggest that B is not obligated to return A's car back to her.

However, not all coercive acts are coercive threats. As David Archard notes, it is also possible to coerce someone through altering the circumstances of the situation.¹⁴ Consider the following situation:

A hurricane is about to hit a city and B decides to flee in her car. However, prior to getting into her car, A drains most of the fuel out of B's car and then follows her. B's car soon runs out of gas in a part of the city that is now completely vacated. A offers to give B enough fuel for her to get out of the city if A agrees to have sexual relations with him as soon as they escape from the path of the hurricane. B agrees.

Unlike coercive threats, A is not in his proposal claiming that he will make B worse off in respect to some baseline. In fact it might be argued that A is not threatening B at all in this instance. However, it is also apparent that acts of what I call "circumstantial coercion" are in many respects very similar to coercive threats. The person doing the influencing wants the person being influenced to do something that she would not otherwise do. And like coercive threats, this is also an instance where the person being influenced is forced to do an action which brings her below a moral baseline as an important moral right of hers is being violated. While B consents to have sexual relations with A, it is nevertheless the case that her right to not be exploited is being violated. As Feinberg points out for A to be exploited it is only necessary for A to gain from B and for A's gain to be unjust in respect to B's.¹⁵ Both of these conditions appear to be met in this case.

Furthermore as is the case with coercive threats, B is not required to uphold the terms of any agreements which arise as a result of being coerced. For example, given the circumstances which lead to B's agreeing to having sexual relations with A, we do not believe that if B reneges on her agreement she has acted wrongly.

For the sake of clarity, it is important to emphasize the importance of both the normative baseline and the upholding agreement requirements. We often limit the

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alternatives of others intentionally, but we do not regard such influences as being inappropriate in many cases. For example:

B is considering having a relationship with either C or D. A however wants B to date D because she thinks C is bad for B and D is good for B. To ensure that B asks out D rather than C, A gets E who also wants to date C to ask C out before B can. Realizing that C is unavailable, B decides to ask out D who agrees.

It seems counterintuitive to hold that A has circumstantially coerced B to ask out D. None of B's rights appear to be violated; it seems strange to think that B has a right against E or anyone else to date D. Furthermore, all things being equal we are inclined to think that despite the circumstances if B reneges on his agreement to go out with D, B acts wrongly.

It is now appropriate to assess the claim that situations can prevent persons from making voluntary decisions in the same manner as these acts. As I have shown in my discussion of coercive acts and what it is to act involuntary, the following criteria need to be met for an influence to prevent persons from acting freely:

- (1) The influence must be difficult to resist or irresistible.
- (2) The influence forces persons to perform an action that they do not welcome because it brings them below a moral baseline.
- (3) The person being influenced is not obligated to uphold the terms of any agreements that result from the influence.

I also showed that there are two mechanisms through which one can be coerced to perform a particular action:

- (1) The person influenced is presented with two options which each brings the person being influenced below a moral baseline, and one of which is considerably worse than the other.
- (2) The alternatives of the person being influenced are limited so that the person is forced to choose a particular option.

Having brought these points to light again, consider the following situation, which Wertheimer presents in his book *Consent to Sexual Relations*:

A patient's leg is gangrenous and she must choose between amputation and death. She understands the alternatives, and because she does not want to die, she signs the consent form.¹⁶

As Wertheimer notes, there is a sense in which "one is 'forced' to do that which there is no reasonable alternative to doing" and A does not welcome either alternative.¹⁷ Yet, it seems strange to think that A is coerced or does not voluntarily consent to having her leg amputated as neither of the alternatives that are presented to A violates any of her moral rights. Suppose that A's leg is operated on and A agrees to pay her surgeon a fee prior to the operation. If this was an instance in which A does not act voluntarily, then it is not wrong for her to fail to pay this fee. However, this seems counterintuitive.

It strikes me that the terminally ill person who is asked to participate in research finds herself in an analogous situation. The terminally ill person is given the opportunity to do something- in this case participating in research, and both the option of participating in research and the option of not participating in research may be viewed in an unfavorable light by the terminally ill person. However, like the previous case,

neither of these options violates the rights of the terminally ill person. Furthermore, it seems apparent that all things being equal if the terminally ill person agrees to participate in the study, then she should be required to abide by the terms of the agreement. Therefore, the factors related to being terminally ill do *not* prevent persons from voluntarily consenting to participate in research. It follows then that terminally ill persons do not find themselves in situations which resemble coercive threats or acts of circumstantial coercion. It should be noted that I am not claiming that there are *no* situations which have all the relevant features of coercive acts. I am merely claiming that the sort of situations that are relevant to this discussion should not be regarded as coercive.

To conclude, in this paper I have argued that it is fallacious to claim that persons who are terminally ill can be coerced into enrolling in research as the situations that such persons find themselves in do not resemble acts of coercion in several key respects.

NOTES

1. S. Stolberg, "On Medicine's Frontier: The Last Journey of James Quinn," *New York Times* 8 Oct. 8 2002; J. W. Berg, P. S. Appelbaum, C. W. Lidz, and L. S. Parker, *Informed Consent: Legal Theory and Clinical Practice* (New York: Oxford UP, 2001).

2. M. Agrawal, "Voluntariness in Clinical Research at the End of Life," *Journal of Pain and Symptom Management* 25 (2003): 25-32; M. Agrawal and E. J. Emanuel, "Ethics of Phase I Oncology Studies: Reexamining the Arguments and the Data," *JAMA* 290 (2003):1075-82.

3. For example, Agrawal and Emmanuel write:

To categorize the choice of patients with advanced cancer to participate in phase I studies as inherently coerced is a serious confusion. By definition coercion is a credible and strong threat exerted by one person that limits or adversely affects the options another person has available. . . . Many patients may feel pushed by nature, fate, and their circumstances to enroll. However, being in situation with limited and difficult choices does not itself constitute coercion. Unless, the adverse choice situation was created by another person, the choice made by the patient should not be labeled as coerced.

This argument is representative of the vast majority of arguments that have been advanced against the claim that situations cannot coerce persons from enrolling in research.

4. W. Rowe, "Two Concepts of Freedom," *Agents, Causes, and Events: Essays on Indeterminism and Free Will*, ed. Timothy O'Connor (New York: Oxford UP, 1995)151-71.

5. H. Frankfurt, "Alternate Possibilities and Moral Responsibility," *Journal of Philosophy* 66 (1969): 829-39, (1969), and L. Ekstrom, *Free Will: A Philosophical Study* (Boulder: Westview P, 1999).

6. H. Frankfurt, "Freedom of the Will and the Concept of a Person," *Journal of Philosophy* 68 (1971): 5-20.

7. T. Beauchamp and J. Childress, *Principles of Biomedical Ethics*, 5th ed. (New York, NY: Oxford UP, 2001) 57-104; J. Christman, *The Inner Citadel: Essays on Individual Autonomy* (New York: Oxford UP, 1989); I. Thalberg, "Hierarchical Analyses of Unfree Action," *Canadian Journal of Philosophy* 8 (1978): 211-225, and S. Wolf, "Sanity and the Metaphysics of Responsibility," *The Inner Citadel*, ed. J. Christman (New York: Oxford UP, 1989).

8. Beauchamp and Childress 57-104.

9. B. Brody, "Making Informed Consent Meaningful," *IRB* 23 (2002): 1-5.

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10. T.M. Scanlon, *What We Owe to Each Other* (Boston: Belknap P, 2000) 114.
11. Beauchamp and Childress 59.
12. A. Westheimer, *Consent to Sexual Relations* (Cambridge: Cambridge UP, 2003).
13. Wertheimer 167.
14. D. Archard, *Sexual Consent* (Boulder: Westview, 1998).
15. J. Feinberg, *Harmless Wrongdoing* (Oxford: Oxford UP, 1988).
16. Wertheimer 123.
17. Wertheimer 172.